MULTIPLE SCLEROSIS - PERCEIVED CONTROL AND COPING - DEVELOPMENT OF A SCALE

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DECLARATION

This thesis has been composed by myself and the work is my own. Treatment interventions were carried out by the multi-disciplinary team members and research assistants were involved in completing the assessment measures specially for the 2nd part of the study.

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ABSTRACT

MS is a significant source of stress for many individuals. It is a chronic disease. The onset most often is in young adulthood. There are no preventative measures. Treatment is limited and often ineffective. For many the disease is characterised by unpredictable periods of remission and exacerbation of symptoms. When the 'flares' are frequent or of long duration, there is often poor coping, including depressive symptoms and impaired quality of life. Coping is an important component in the management of this disease. Perception plays a major role in coping. Literature search showed no evidence of any research on the topic of perception of coping and chronic illness. The aim of this study is to devise an appropriate measure of perception of coping in patients suffering from MS.

The study is divided into 2 major parts. Part 1 is the devising of the scale. Part 2 is designed to establish reliability and validity of the scale. This part of the study is also designed to investigate the effectiveness of conventional rehabilitation programmes in altering the coping perception. For the first part of the study 20 subjects were recruited from the MS Register kept at the Douglas Grant Rehabilitation Unit. The second part of the study also comprised 20 subjects and these subjects were recruited when they were referred for rehabilitation to the Unit. The validity of the Scale was attempted by using the HAD scale, GHQ, and the COPE scale. Validation of the PCS as well as the impact of CBT intervention were attempted with a group of chronic pain patients. Reliability of the scale was established but not the validity. The reasons for this are discussed.

1. INTRODUCTION

1.1 Multiple Sclerosis - The Disease

Multiple Sclerosis (MS) is among the most predominant neurological disease and is particularly prevalent in the northern areas of temperate climate (Matthews, Acheson, Batchelor, and Weller, 1985). The ratio of women-to-men affected ranges from 2:1 to 3:1 (Schienberg, 1983). MS occurs in relatively young people and has a prolonged course. Onset is most frequent during the years of young adulthood, between the ages of 20 and 40 (Seland, 1984; Walker, 1982). However, the disorder is typically difficult to diagnose in its early stages owing, largely, to three factors; a) the variability of its course, b) the transient nature of early symptoms and, c) the unavailability of a specific diagnostic test (Seland, 1984). As a result of these factors the 'diagnosis' on average can take up to 4 to 5 years. It is also common to have symptoms without objective clinical findings and vice versa (Willoughby and Paty, 1990). The 'diagnostic' process itself typically involves uncomfortable procedures and disruptive hospitalisation.

Multiple Sclerosis is a chronic progressive degenerative neurological disease that produces demyelination of the central nervous system axon, resulting in delayed or blocked transmissions of nervous impulses (Hallpike, Adams and Tourtellote, 1983; McFarlin and McFarland, 1982; Walker, 1982). A wide and often confusing range of symptoms can be seen including weakness and tiredness, loss of sensation, visual impairment, poor co-ordination, spasticity, bladder disturbances, sexual dysfunction, and cognitive changes (Goldstein, Siroky, Sax and Krane, 1982; Hallpike et al, 1983; Matthews et al, 1985; Walker,

1982). Although the disease itself is not commonly considered as fatal, life expectancy may be affected by the hazards of complication, the most common being respiratory and urinary infections (Vander-Plate, 1984).

MS is characterised by an extremely variable progression of relapses (or exacerbations) and remissions, making it impossible to predict the course in the majority of cases. In the words of Burnfield and Burnfield (1982, p149), "The disease typically presents a confusing and transient constellation of symptoms". The general ultimate trend, however, is one of progressively increasing deterioration and disability. More severely disabled individuals may eventually require a wheelchair and, ultimately, may be confined to bed. Many MS symptoms are "invisible" in so far as they cannot be observed directly, and they may fluctuate markedly (e.g., fatigue, visual and other sensory disturbances). Although many of the complications associated with the condition may be amenable to treatment, in some cases there is currently no cure and little symptomatic relief for the disease (Hallpike et al, 1983; McFarlin and McFarland, 1982). In addition to difficulties attributable to fatigue, disability, and functional loss, MS can affect the lifestyle of the individual by undermining the individual's optimism, enthusiasm and long term planning by an unforeseen exacerbation episode (Devins and Seland, 1987). Thus MS becomes intrusive into lifestyle, activities, and interests.

1.1.2 Impact

Sibley (1990) reported anxiety, depression and dread as the most commonly experienced features of MS. In addition, the author reports that about 20% of patients have a mild form of the disease with rare exacerbations and little disability; 20-30% have recurrent episodes of acute illness that produce a

moderate degree of persisting disability (relapsing - remitting MS); and 50% to 60% show progressive deterioration without clear-cut exacerbations (chronic - progressive MS). "Although 20-30% of people with MS do not become severely disabled, there is no way of knowing who will be spared" (Sibley, 1990, p 228). Adding to this unpredictability is the direction , nature and severity of the symptoms. Generalisation of these features is difficult. The experiences of each individual are unique giving rise to questions such as whether a particular symptom is due to the disease. This frequently poses confusion for patients, families, and care givers.

Symptoms of MS may appear at any time between the ages of 15 and 50 but the onset is most often between 20 and 40 years (Baum and Rothschild, 1981; Sibley, 1990). This is a critical time in people's lives, when individuals are beginning to build families and establish careers. In building families, various fears have been reported. The more common of these concerns are the impact of pregnancy on MS, the fear of passing the MS to the child, and the fear that one cannot care for a child if the disability progresses (Doolittle, Myers and Lehrich, 1990). Worries about career advancement and the impact of stress are very similar (Warren, 1990). La Rocca (1984) and Kornblith, La Rocca and Baum, (1986) highlighted in their research that between 52% and 85% of people with MS are unemployed. They showed that before reaching that point "most people have had to cut down on the number of hours they work, change their schedules, or assume less demanding and challenging kinds of work", hitherto incurring economic strain due to loss of income. The disease also has a large impact on family and social life.

Marital conflict, difficulty performing usual family responsibilities, and distressed parent-child relationships are reported in one-half and three-quarters

of families studied by Power (1985) and Braham, Houser and Cline, (1975). They also reported evidence of high levels of dysphoria, anxiety and interpersonal and behavioural problems in children of parents with MS.

Social isolation is very common. Braham et al's (1975) study found that 40% of people with MS spent most of the day alone. Leisure activities that require motor skills such as dancing, tennis and outdoor activities are also given up early in the illness. High fatigue levels can also contribute to diminished leisure. Emotional difficulties are therefore common among these people due to the above-mentioned medicopsychosocio factors. This will be discussed in more detail in the following section.

1.2 **Emotional Aspects of MS**

Given this diversity of confusing symptoms, diagnostic difficulties, unpredictable course, unknown aetiology and lack of specific direction, one might expect a variety of emotional and behavioural consequences. Indeed MS has been recognised as introducing a number of psychological issues and adaptive demands into the lives of sufferers and the members of their families.

1.2.1 Early Research

Early attempts to clarify the function of emotional factors in MS began around the turn of the century (Bramwell, 1917; Jelliffe, 1921; Langworthy, Kolb and Androp, 1941; Russell, 1911) and the investigative orientations depended upon psychoanalytical and individual case histories or the use of Rorschach test (Harrower and Kraus, 1951).

The main focus of the early studies was to ascertain personality patterns and psychopathology in patients diagnosed with MS.

1.2.1a *MS and Personality*

Blatt and Hecht (1951) demonstrated with the use of Rorschach's Test that about half of their group of 21 patients showed response patterns suggestive of a 'hysterical' personality. Their conclusion was that hysterical personality was compatible with the disease itself. Authors such as Inman (1948) and Langworthy(1950) went a step further to state that conversion hysteria actually produced the neurological changes manifested by MS.

Harrower (1950) attempted to demonstrate this further by using a battery of psychological tests, including Rorschach and Wechsler Bellevue Tests. The author studied 61 MS patients and compared them with 100 "normal" subjects, 200 patients diagnosed as suffering "psychosomatic problems", and 70 Parkinson's and poliomyelitis patients. Harrower concluded that MS patients showed greater dependency needs, an absence of body-centred anxiety and greater aspects of submission and surrender when compared to the other groups. The author attributed this pattern of responses to a "premorbid personality structure" and indicated that psychological attributes render the individual susceptible to the disease. However, there are several limitations to this study. Firstly, the comparison groups were not truly comparable along the dimensions of disease or disability. Secondly, the validity of projective measures in general is limited and the relevance of the use of projective measures with medical patients is questionable (Vander-Plate, 1984) making it difficult to arrive at a meaningful interpretation.

In a later study Harrower and Kraus (1951) attempted to investigate whether psychological components predispose an individual to MS. Using projective measures, they examined 140 MS patients and found that the most dependent, those with the most personality problems, and those with a lack of somatic concern were among the patients with advanced disease. It was suggested that patients in remission demonstrated a "capacity for richer psychological experience" and "expanded personality" (p45). Due to the changes that are observed as the disease progresses, they concluded that the conditions imposed by MS resulted in observed changes rather than the initial question the authors attempted to investigate, that is, that psychological characteristics predispose the person to the disease.

They felt that many of these people were extremely dependent, with an almost complete absence of "body centred" anxiety, a minimum of inner conflicts and a tendency to view the world unrealistically "through rose-coloured glasses". This study is subject to the same limitations as the previous one.

Philippopoulos, Wittkower and Cousineau (1958) attempted to show the relationship between premorbid personality functioning and emotional disturbance in MS. They examined 40 MS patients and 40 control subjects consisting of patients with chronic cervical spondylosis, patients with lumbar disc complications, and healthy nurses. Using projective and intellectual testing and general history taking, they concluded that MS patients experienced unhappy childhood, rejection by parents, and emotional immaturity and anxiety more often than controls. They proceeded to explain that emotional disturbance may hasten the onset and exacerbation of MS.

Again, this study is subject to the same criticisms as the previous two, in addition to the fact that the control group was not comparable along disease or disability dimensions.

The use of projective tests as reliable indicators of personality variables is seriously questionable in MS, as the great majority of individuals with MS are not psychopathological but rather are relatively "normal" persons attempting to cope successfully with the stress and psychosocial issues the disease presents (Vander-Plate, 1984). In addition there is also the high reliance on subjective interpretation which renders these studies invalid, particularly in the light of modern psychological investigative techniques, such as the use of standardised psychological assessment measures.

Canter (1951) studied 31 male patients in the early stages of MS. The author assessed these patients by using the MMPI and concluded that "a neurotic overlay" is present in MS patients directing to a personality profile of hysteria characterised by depression, body anxiety and increased levels of self concern. Similar results were reported in Shontz's (1955) study.

In essence what these studies are highlighting is that emotional distress is a natural response to a newly diagnosed disease.

Bourestom and Howard (1965) studied 74 newly hospitalised MS patients and compared them with 94 rheumatoid arthritis and 100 spinal cord injured patients to ascertain if personality profiles were unique to each disability or if patterns reflected reactions to any form of chronic illness. The authors found no significant difference between the groups in terms of personality profiles and the MS patients showed no more psychopathology than the other two groups.

This study also suggested that male MS patients showed more distress, depression and somatic concerns than female MS patients, and this supports Canter's (1951) conclusion. However, Bourestom and Howard's (1965) study has the following limitations: lack of control for chronicity, severity and age.

1.2.2 Conclusion

Research well into the 1970's continued to focus on: delineation of a uniform MS personality, "premorbid" psychological characteristics, or emotional response to the disease, (Cleeland, Mathews and Hopper, 1970; Gilberstadt and Farkas, 1961; Goodstein and Ferrell, 1977; Peyser, Edwards and Poser, 1980). These early studies set the stage for later investigations.

1.3 **Later Research**

The volume of psychological studies in the 80's focused on a wide range of emotional responses in MS patients. The most commonly identified ones were anxiety, stress, and depression. These emotions were seen either as arising from the disease activity; which involves the onset of illness, exacerbation or the progression of symptoms, and/or as a result of loss of function, i.e., physical incapacitation due to deterioration produced by the disease.

Maybury and Brewin (1984) studied 36 MS patients and assessed the emotional impact by using the General Health Questionnaire short form (12 items) and the Rosenberg Self Esteem Scale. They found that functional loss was not related to emotional impact. Zeldow and Pavlov (1984) contradicted this finding. They looked at 81 MS patients and assessed the emotional impact by using the

California Psychological Inventory and the Interpersonal Dependency Inventory using specifically the number of "meaningful social contacts". They concluded that increased functional loss was significantly associated with:

a) decreased psychosocial well-being

b) increased interpersonal dependency and

c) fewer meaningful social contacts.

Their study demonstrated that functional loss contributed to emotional impact. However, both these studies indicate that it is difficult to tease apart the disease activity and functional loss, rather these were seen as correlational.

Similarly, Goodstein and Ferrell (1977) reviewed 200 articles concerning the relationship of emotional symptoms to MS. They found that only 15 articles reported emotional difficulties, which were known to occur prior to overt physical symptoms and just 5 suggested that a common physiological process might exist. No study from their review addressed the clinical importance of depressive illness as a presenting feature in MS.

1.3.1 Depression and Unpredictability

The research findings of depression in MS have varied. Joffe, Lippert and Gary (1987) and Schiffer, Caine and Bamford (1983) reported an increase in the rate of depression between 25% and 54% in MS but Surridge's (1969) study found no significant increase of depression in MS. McIvor, Ricklan and Reznikoff (1984) for example, reported a positive correlation between the disease severity and

depression, while Maybury and Brewin (1984), Joffe et al (1987) and Dalos, Rabins, Brooks and O'Donnell (1983) failed to show this relationship.

The unpredictability of the disease has been said to contribute to the psychosocial impact of MS as this relates to the extent of loss and suffering that a person perceives to be the inevitable consequences of the illness. This was reported by Peyser, Edwards and Poser's (1980) study. Their subjects were 55 MS in and out-patients. Using cluster analysis they identified six sub groups. Three of these displayed pathologically elevated profiles and the elevated distress was associated with "moderate" physical impairment. However, the highest levels of distress were noted among the recent onset patients with limited disability. Their results indicated generally non-disturbed levels of psychological functioning.

As in the 1970's research, these studies also have their limitations because they have used scales which only include somatic symptoms of distress, and this may be attributable to the underlying medical conditions rather than the emotional impact of the illness itself.

1.3.2 Depression as a sign of neurological disease activity

Another persistent issue in MS is whether depression is a direct product of the disease or whether it is a response to the illness and the stress associated with it.

Some researchers have speculated that depression and distress may contribute to the underlying neurological disease process of MS (Grant, 1985; Paulley, 1985). These researchers attempted to explain the process using a "Diathesis stress Model". This model attempted to explain that the development of MS

was believed to be produced by the actions of "emotionally conditioned vasomotor responses in the central nervous system", among those who had been exposed to unusually stressful life circumstances. Unfortunately, these studies failed to measure the specific mechanism hypothesised, in addition to experimenter bias distorting the results.

Whitlock and Siskind (1980) also attempted to investigate this process. They studied 30 MS patients using interviews and the Beck Depression Inventory. They found that MS patients reported more episodes of endogenous depression both prior to and following the onset of the disease than the control subjects with other neurological syndromes. They concluded that "serious affective illness can be a premonitory or complicating symptom of MS or a complication that is likely to be secondary to cerebral damage caused by the disease" (pg 864). Whitlock and Siskind based their conclusion solely upon three case histories in which depression was "episodic in nature" and unresponsive to usual treatments. Likewise Goodstein and Ferrell (1977) after surveying 200 papers on MS found that only 15 papers reported the occurrence of affective disorder before the onset of neurological symptoms. Such a conclusion would lead one to expect that psychological treatments for depression in MS patients would be destined to fail. Besides, Whitlock and Siskind based this conclusion solely upon 3 case histories in which depression was "episodic in nature" and unresponsive to usual treatments.

Both these studies can be questioned based upon the unreliability of retrospective report and were confounded by disease variables. The diagnostic process is also found to be imprecise and often requires considerable time. Therefore, depression may occur in response to onset of symptoms but pre-date diagnosis.

Other investigators have speculated that changes in affect may actually be a clinical sign of active central nervous system disease, as shown by Schiffer, Caine, Bamford and Levy's (1983) study. They studied 30 MS patients, 15 of whom were with predominantly 'cerebral involvement' of their myelinating disease and 15 'non cerebral' group with spinal cord and cerebellar involvement. A group of normal volunteers served as controls. Assessment included neuropsychological testing, the use of the Beck Depression Inventory and a psychiatric interview. They found that there were significantly more depressive episodes in the 'cerebral' group. This group of patients suffered hemiparesis with sensory loss, convulsions, aphasia, homonymous hemianopia, abnormal EEG and CAT scan. They concluded that depression episodes depended more on the neuroanatomic location of the demyelinating disease and there was no evidence of depression as a neurologically based sign. However, Joffe et al (1987) who attempted a similar study did not demonstrate this. Rao, Reingold and Ron (1993) found that MS patients with mild to moderate cognitive impairment reported more depressive symptoms than patients without cognitive impairment or those with severe cognitive impairment. A further confusing element in MS is that many symptoms of MS are similar to the symptoms of depression. Problems in concentration, memory and chronic marked fatigue can give the appearance of depression when infact it is the MS disease activity (Devins and Seland, 1987; Minden, 1987)

1.3.3 Conclusion

These studies unfortunately did not show any specific mechanisms contributing to the changes in affect and MS. Therefore it can be concluded that there has

not yet been an adequate test of the hypotheses that depression is a direct sign of MS disease activity.

1.3.4 Depression and Cognitive Impairment

Another line of enquiry has been in the areas of cognitive and intellectual deficits associated with advanced MS that may be compounded with depression and mood disorders (Peyser and Becker, 1984). Studies by De Paulo and Folstein (1978) and Peyser et al (1980) concluded that cognitive deficit (eg, reduced abstract reasoning ability) and depression are independent of each other. These studies also indicated that cognitive deficits are unrelated to a patient's degree of physical disability. In a similar line Heaton, Nelson, Thompson, Burke and Franklin's (1985) research reported systemic relation between the severity of cognitive deficit and degree of neurological impairment. These studies do not show evidence for a relationship between depression and neurological signs of MS. These studies are also of questionable validity because of the reliance on self report of psychological stresses, as these self reports can be misinterpreted and influenced by "MS-produced intellectual change".

1.3.5 Stress

It is always stressful for a person to hear the diagnosis of MS (Hendron, 1993). Previously healthy, he or she now must adapt to the reality of symptoms and problems, the possibility of increasing neurological deficit and disability, altered expectations and plans and an uncertain future. It is therefore common for the patient to experience clinical features such as denial and isolation, anger,

bargaining, depression and eventually acceptance; a process similar to bereavement (Burnfield and Burnfield, 1982).

A major time of stress for some MS patients, is the period during which their symptoms are being investigated and the cause has not yet been explained or the onset is less clear and the physician may suspect other causes. In other cases, the symptoms may be vague and non specific and there can be a long period during which, the patient know something is seriously wrong, but is unable to receive definitive answers.

Stewart and Sullivan (1982) reported that "while, patients are in the dark about their medical status, they are unwell, expected to function normally without the physician sanctioned sick-role and often under the suspicion of family, friends, employers and even themselves, of being hypochondriacs or malingerers".

In many situations patients themselves may begin to establish their own diagnosis, increasing further the conflicts with their families, friends and physicians.

From the nature of this illness, it is clear that a chronic disease like MS induces many stresses, but can the stress activate the pathological changes that produce acute attacks and progression of the disease?

There are a few reports available in the literature which examine the possible link between emotional stress and the exacerbation of MS but the results reported are conflicting. Brickner and Simons (1950) investigated whether stress had triggered the exacerbation of symptoms in MS. They studied 50 MS patients and found that only 14% of these patients reported that "exacerbations

had occurred during or following a period of unusual stress". This was an uncontrolled study and no validated stress measurement tools were used. McAlpine, Compston and Lumsden (1955) again reported from their uncontrolled study that 33% of their MS subjects encountered temporary exacerbation of symptoms during or immediately after stress. Pratt (1951) in his controlled study reported that 25% of MS patients experienced emotional disturbances preceding relapses. He also found that significant differences existed between the MS patients and the controlled subjects in response to specific emotional stimuli. He found that the control subjects who were neurological patients, reported specific emotional stimuli precipitating a relapse within minutes of the occurrence, while the MS subjects reported a delayed response to this. However, there was no evidence of any difference between the two groups in terms of the occurrence of relapse following prolonged stress. Pratt gave little information on the nature of his control group and like the first study, he used no validated measure of stress. As a result of this inappropriateness of measure the potential for relapse was difficult to judge.

Rabins and Brooks (1981) studied 87 MS patients by requesting them to fill in a monthly life events diary over a one year period. Twenty-three patients were said to have experienced exacerbations. Comparing these patients' scores in the month during which they reported an exacerbation to the scores for all previous months the authors found no significant difference. However, the life events scores of patients experiencing an exacerbation were not compared to those patients in remission. There is a possibility that patients experiencing exacerbation of symptoms had been experiencing prolonged high levels of stressful life events, therefore "patients as their own control" approach would not show a change in the scores. On the other hand, it is important to be aware that the impact of stress that is significant rather than the stressful events

themselves. Although Rabins et al collected a monthly emotional disturbance score using the General Health Questionnaire they did not examine the trend of relapsing patients' scores on this variable.

Dalos, Rabins, and Brooks (1983) in their study found that the GHQ scores, completed by patients, in the months when they experienced an exacerbation were higher, than GHQ scores completed during months when they were in remission. In addition, Dalos et al (1983) and Logsdail, Callanan and Ron (1988) also observed that there was a trend towards higher anxiety in the relapsing patients. They reported morbidity to be significantly correlated with patients' perception of stress and lack of social support, regardless of whether they were in exacerbation or remission, although they saw no association between exacerbations and psychiatric symptomatology. Logsdail et al's study only had a total of 76 MS patients; 28 in exacerbation and 44 in remission, therefore the ability to detect an association between remission and exacerbation and morbidity is limited. Other studies such as Mei-Tal, Meyerowitiz and Engel (1970) cited a number of stressors. They reported that stressors precede onset and recurrences, including protracted tension, such as added responsibility or marital conflict, and acute stresses such as death in the family, surgery, and even marriage of a sibling.

Philippopoulos et al (1958) found that 35 out of 40 patients studied, reported that prolonged emotional stress preceded the onset of MS. Acute emotional upset preceding the disease was much less common.

Warren, Greenhill and Warren (1982) studied the emotional states and the occurrence of stressful life events within two years prior to MS onset. Significantly, more MS patients than controls reported that "congregation of

events they had experienced placed them under more unwanted stress than usual during the two years immediately prior to the onset" (p 826). This was interpreted by the authors as supportive of the stress-illness onset hypothesis. Again interviewers could not be kept blind to the diagnostic status of participants and the data was retrospective in nature, so that memory distortion or experiment bias effects cannot be ruled out. This is acknowledged by the authors themselves. Franklin, Nelson and Heaton (1988) studied 55 MS patients with relapsing and remitting symptoms and followed them up for a period of 20 months on the occurrence of stressful life events. This was carried out every 4 months. The patients who reported significant negative emotions on controllable events were said to be 3.7 times more likely to relapse. Grant, Brown and Harris (1989) in their retrospective control study investigated the effect of emotional and environmental stress prior to the onset of MS. They compared recently diagnosed MS patients to controls. They found that there was a significant marked life stress in the 6 months prior to the onset of the disease. They observed that the rate of recent marked stress among patients in exacerbation was similar to the rate reported by patients experiencing their first attack. They concluded that greater life adversity precipitated relapse.

1.3.3 Conclusion

It can be said that many patients and neurologists tend to attribute great importance to the role of stress in MS. Nevertheless, in spite of numerous studies from the literature there are very few sound conclusions that can be drawn. The logical short comings such as retrospective design, unreliability of patient report, lack of standardised measurement and small sample size make interpretation of results difficult. Prospective studies, which monitor stress over time and record exacerbations as they occur, may be more meaningful in terms

of establishing a causal relationship. It is also important to emphasise that until physiological indicators of disease activity replace clinical or subjective measures, even prospective studies will not be able to clearly demonstrate that stress precedes exacerbations. Therefore, it might best be concluded that the relationship between stress and MS has not yet been adequately tested.

1.3.7 General Conclusion

On the basis of the literature reviewed so far on emotional aspects of MS, few conclusions can be drawn concerning the relationship between emotional factors and MS. While early studies suggested the presence of hysterical personality in persons with the disease, overall there is no compelling evidence that a uniform MS personality does exist. One finding, however, does appear supported: the psychological symptom most frequently associated with the disease is depression (Baretz and Stephenson, 1981; Goodstein and Ferrell, 1977; Whitlock and Siskind, 1980; Schiffer et al, 1983). Although some have speculated that depression is physiologically linked with MS there is no good evidence to support that contention. Instead, current thinking views depression as one response frequently experienced in the adjustment process, as is seen with most chronic illnesses. The lack of knowledge is in part the result of serious flaws in research design and methodology. However, in addition to the drawbacks in design and methodology due to the complex problems inherent in MS it might not be possible to determine causality or ascertain precise emotional mechanisms involved in the disease.

1.4 Coping

1.4.1 Introduction

Research to date has generally been restricted to the investigation of a single life domain and has not examined the psychological impact that may accompany such changes. Theoretical links between disruptions and their impact on psychosocial outcomes have neither been formulated nor tested. This is a significant omission in so far as the development of new knowledge is concerned. Clinical interventions must be founded upon a scientifically validated theoretical account of the psychosocial impact of chronic disabling illnesses such as MS.

Devins, Seland, Klein, Edworthy and Saary (1993) introduced the construct of illness intrusiveness which leads to the disruption of valued activities and interests. This, they said, is especially so in chronic disabling illnesses such as MS. They identified three mechanisms that exert this disruption, (a) through the reduction of the availability of positive or rewarding experiences, (b) through decreased involvements in valued activities and interests and/or (c) through the reduction of personal control over important domains of life experience (i.e., by compromising the individual's ability to obtain positively valued outcomes or to avoid negative ones).

In MS they identified the burden of illness, contributing to the functional deficits which, in turn, contributed to physical disabilities. They concluded that "all other factors being equal, each of these categories of disease characteristics is hypothesized to contribute to more global life-style disruptions by interfering

with continued involvement in valued activities and interests (i.e., illness intrusiveness), resulting in compromised psychosocial well-being".

Binik, Chowanel and Devins (1990) and Devins, Edworthy, Guthrie and Martin's (1992) findings have supported these assertions in end-stage renal disease and Rheumatoid Arthritis.

1.4.2 Rationale

It is a well documented fact that adult physical health, is closely linked with emotional and mental health (Murray, 1995). However, there are differences in how individuals adjust to this, let it be acute or chronic illness. Coping efforts have been suggested as one means of accounting for these differences in adaptation. Coping has been defined as the "constantly changing cognitive and behavioural effort (used) to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p141). There are many studies that have documented the importance of individual coping efforts in helping adults maintain reasonable levels of emotional well-being despite the physical illness (Cohen and Lazarus, 1983; Moos and Schaefer, 1985). These studies have shown that typical coping strategies include: selective ignoring, denial, taking refuge in activity, information-seeking, learning the specifics about the illness, wish-fulfilling fantasy, and seeking comfort from others.

Studies investigating stress other than physical illness have also provided evidence that adults' choices of coping strategies influence the emotional outcome of stressful events (Menaghan, 1982; Pearlin and Schooler, 1978). Over a four year period, Menaghan (1982) studied the role of coping in marital

problems. They found that making optimistic comparisons of one situation relative to the past and relative to one's peers was associated with both lowered distress and with fewer subsequent marital problems. Pearlin et al (1978) confirmed that coping affected depression in reaction to involuntary job disruption. People who coped by making positive comparisons of their situations with others and by devaluing the importance of monetary success were more successful in avoiding economic stress, loss of self-esteem, and depression.

1.4.3 Coping Strategies

It has been suggested that specific types of coping strategies are more or less effective, depending upon the type of stress being faced. Pearlin and Schooler (1978) found that coping strategies involving commitment and engagement with others were most effective in dealing with stresses arising in close interpersonal relations. In contrast, cognitive manipulations that distracted the person from the problem were most effective for stresses in occupational and economic areas, areas that are more impersonal and less amenable to control.

Billings and Moos (1981), Folkman et al (1980) and Cohen et al (1983) identified two factors that play crucial roles in coping, the emotional well-being and the perception of uncertainty about the situation and how he or she copes with this uncertainty. "Uncertainty" is defined by Mischel (1988) as the inability to determine the meaning of problem-related events. Billings and Moos (1981) describe these types of coping as the problem-focused and emotion-focused coping. Problem-focused coping comprised those coping strategies directed at managing or altering the source of stress and emotion-focused coping those

strategies directed at regulating emotional responses and distress that occur as a consequence of the problem.

It has been documented that Emotion Focused and Problem Focused Coping are used in any one stressful situation but there is evidence to show that coping behaviours differ depending on the individual's appraisal of the event and the context in which this appraisal happens. Folkman et al (1980, 1985, 1986) in their cross-sectional studies of healthy community populations stated that Problem Focused coping methods such as confronting the problem, accepting responsibility, and reappraising the situation positively are applied when an individual evaluates the stressful event as manageable or alterable. If the event is perceived as having to be accepted then Emotion Focused strategies such as escape-avoidance or distancing are used to manage emotions and feelings. Emotion Focused Coping is said to be used more frequently in a situation where stress is related to health. Problem Focused Coping is used with work and stress at work (Folkman & Lazarus, 1980).

1.4.4 Ill Health and Coping Strategies

In health care situations the relationship between uncertainty and coping is unclear. Christman, McConnell, Pfeiffer, Webster, Schmitt and Ries (1988); Redeker (1992) and Webster and Christman (1988) have found that illness uncertainty is associated with stress and the role of Emotion Focused Coping is associated with higher levels of anxiety, depression and distress. They also postulated that support for the relationship between illness uncertainty and Problem Focused Coping is much weaker. Mischel (1992 & 1988) reported that the inability to find a significant relationship between uncertainty and Problem Focused Coping may be due to an intervention variable, mainly appraisal of

illness uncertainty as a danger or an opportunity, was not measured. Mischel stated that when the situation is appraised as a danger, coping strategies are used to regulate the emotional arousal associated with it and to reduce the uncertainty. Later, the author continued to postulate that when the arousal is brought under control, the individual handles the uncertainty by using Problem Focused Coping strategies.

Research evidence for the relationship between Emotion Focused Coping and Problem Focused Coping and emotional well-being is equivocal. McNett (1987) and Wineman (1988) both pointed out that Emotion Focused Coping when considered, has been frequently associated with negative emotional outcome in people with neurological disease (Bombardier et al, 1990; Mischel et al, 1991). Mischel, Padilla, Grant and Sorenson (1991) studied 131 women subjects undergoing intervention for gynaecological cancer, and the results highlighted that Focus on Positive, a Problem Focused Coping behaviour and opportunity appraisal reduced emotional distress. In contrast, Bombardier, D'Amico and Jordan (1990) reported that the 101 subjects studied by them showed that the Problem Focused Coping was unrelated to illness adjustment with a variety of chronic illnesses.

1.4.5 MS and Coping

Adjustment to any chronic disease is challenging and difficult for different reasons. The disease MS is one which fits into the chronic disease category, the reasons are described below. Firstly, the disease is not well understood. It is described as a "chronic progressive degenerative neurological disease that results in the demyelination of the central nervous system axons with consequent disruptions in the transmission of nerve impulses" (Devins and

Seland, 1987, p363). There is no specific aetiology of the disease and there is inadequate symptom relief and no cure (Devins and Seland, 1987). Secondly, the symptoms of the illness vary from person to person and can even vary within the same person at different times (Seland, 1984). Thirdly, the disease itself is very hard to diagnose because there is no definite test. Misdiagnosis is often common and correct diagnosis can be prolonged, giving rise to uncertainty and thoughts for other serious disease (Seland, 1984). Fourthly, once diagnosed, the development of the disease is variable (Devins and Seland, 1987); exacerbations and remissions are common and the intensity and extent of the symptoms cannot be predicted. The last factor surrounds the hardships experienced by MS patients adjusting to this disease.

In discussion with MS patients, they often recount that the uncertainty about their well-being is the most frustrating aspect of the disease and having to constantly adjust to the changing circumstances usually in a downward direction. As a result of this uncertainty, their inability to plan the future is another area that is seen as a difficult aspect. They worry about whether they will turn out to be like other MS patients (worse off than themselves) they see in the clinics or at meetings. Concerns about the future and about how long they will be able to continue to be independent are also of concern. As mentioned, many aspects of MS are stressful and individuals develop methods of coping. They may develop methods of coping that are directed to changing the environment or changing the meaning of the event How threatened the person feels and what coping strategies he or she uses depends to a great extent on what resources he or she feels are available. When life events become overwhelming, individuals tend to view the situation as beyond their control and will be more likely to use emotion-focused coping strategies to manage the demands. Coping is a continuous process and how each individual appraises

each situation influences which coping strategies will be used in any particular encounter (Lazarus & Folkman, 1984).

Professionals and carers can allay some of the fears but patients themselves will have some coping strategies to handle the situation they find themselves in. It is common knowledge that some individuals are able to turn life's problems into opportunities, whereas others have trouble seeing their way through an ordinary day. Arklie & Murray (1992), using the Jaloweic Coping Scale, found that the coping styles most frequently used by MS patients were optimism and self-reliance and the most frequently used coping strategies were humour, thinking positively, learning something new, wishing the problem would go away, and attempting to keep life as normal as possible. The authors also reported that the strategies less often used by these patients were blaming someone else, escaping the situation, telling oneself the problem was unimportant, and doing something risky or impulsive. Clinical experience would suggest that people bring their attitudes and coping behaviours into the illness but as the disease progresses, some good copers continue to be effective and some average or poor copers may get worse and decompensate even early in the disease. The question then arises as to why some individuals are good copers and others are poor copers. In order to answer the question, it is important to be guided by a well developed theory. One such method is developing a general theoretical framework to demonstrate the process involved in the adaptation to the disease mechanism.

In addition, something as variable as long term adaptation to chronic illness is likely to involve numerous interacting factors, therefore it is important to have a well developed theoretical framework to take these factors into consideration and guide the process.

1.5 **Theoretical Framework**

The framework to be adapted for this group will be the stress-and-coping theory of Lazarus & Folkman (1984). This theory has been demonstrated to be of value in many areas of study of stress and adaptation. There is much work carried out in the areas of community sample for whom checking health and associated functional limitations have been significant issues (Folkman & Lazarus, 1980). It is felt this theory is likely to be able to explain the process of coping in chronic illness such as those with MS.

1.5.1 Working Model

From this theory it was determined that a working model will be derived to explain the direct effects of disease activity and also to ensure that the model is context specific. This model follows a similar model that was used in Smith & Wallston's (1992) study of patients with chronic rheumatoid arthritis. This model aims to describe both the influence and the effect of coping; and as a result, the development of a particular style of coping.

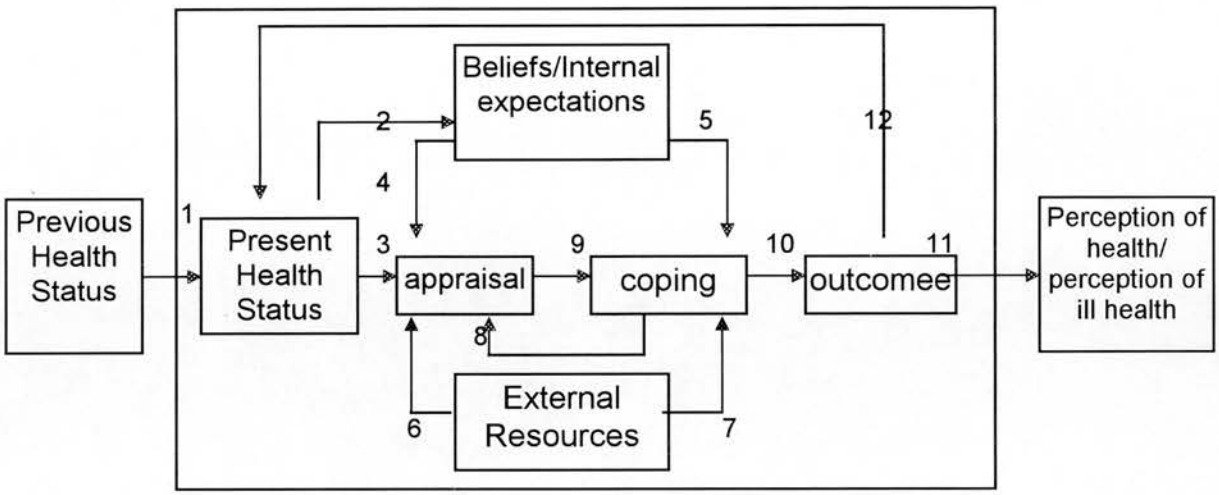


Fig. 1 Theoretical model of coping.

The numbers used in figure 1 are to label the directional paths influencing coping. In this model the appraisals are decided upon by three components, the main one being current physical or health status with respect to the disease (e.g. the extent of impairment and disability). This is a significant determinant of the situation to be appraised. The remaining two factors influencing the appraisal process are the beliefs and expectations regarding one's internal abilities and the availability of external resources which include social support, etc. These two factors can be affected by the perceptions the individual holds at that point in time.

According to this model, coping approaches are mainly determined by appraisal of the present health status and this is helped by the resources, expectations and the beliefs surrounding the individual and the status. For instance, interpreting the disease as a challenge to be overcome promotes active

coping while interpreting a disease as a harm to be overcome promotes passive coping.

Although appraisal is proposed as the initial component of coping beliefs and expectations, any external resources can also directly influence coping. For example, during exacerbation of MS symptoms an individual may engage in active coping, if the individual is competent, or if he/she received encouragement and has a support network. This may occur despite appraisals of helplessness. In this model coping can also directly manipulate appraisals (e.g. by refusing to accept one's limitation) and external resources (e.g. by seeking support).

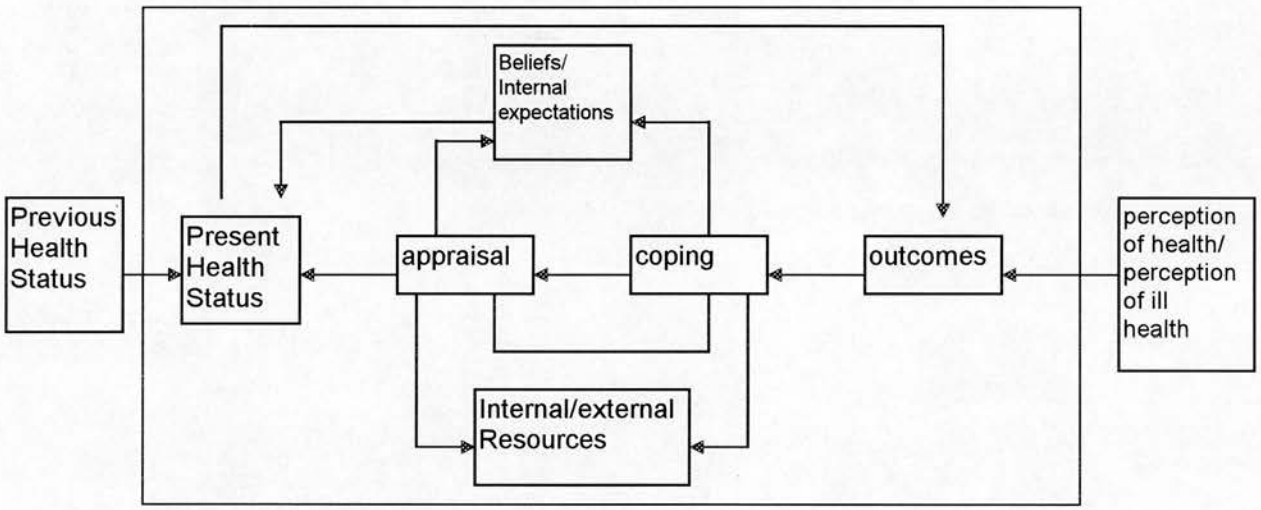


Fig. 2 Theoretical model of coping.

This model should be viewed as an interactive dynamic model which over time will express itself as shown in fig 2, through interchangeable influences, for example, outcomes influencing future coping, hence affecting the future

appraisal process and the beliefs and expectations. This in turn will affect the future Health Status.

Another way of describing this model is in terms of locus of control. This generally refers to the individual's perception of a situation and the reinforcement and rewards related to that situation. This can be explained as either internal locus of control or external locus of control. The concept of Internal and External (I-E) refers to the degree to which an individual perceives the events that happen to him/her as dependent on his/her own behaviour or as a result of luck, chance, fate, or powers beyond one's personal control and understanding (Rotter, 1966).

1.5.2 The I-E Dimension

Rotter's social learning theory (Rotter, 1954, 1975, 1966) provided the general theoretical background for this construct. Rotter (1966) devised a measure of locus of control called the Internal-External Locus of Control (I-E) Scale, which ascertains if an individual demonstrates a predominantly internal or external locus of control.

The locus of control continuum suggests that a person has both internal and external beliefs regarding the concerns of various life events. What characterises a person as internal or external, however, is his or her current prevailing locus of control view. To cope successfully in society, most people need a locus of control in the mid range (Rotter, 1966).

Rotter (1966) defined locus of control as follows: "when a reinforcement is perceived by the subject as following some action of his own but not being

entirely contingent upon his action, then in our culture, it is typically perceived as the result of luck, chance, fate, as under the control of powerful others, or as unpredictable because of the great complexity of the forces surrounding him. When the event is interpreted in this way by an individual we have labelled this as a belief in external control. If the person perceives that the event is contingent upon his own behaviour or his own relatively permanent characteristics, we have formed this belief in internal control" (p1).

Rotter (1966) notes that the effect of reinforcement "is not a simple stamping in process but depends on whether or not the person perceived a causal relationship between his own behaviour and the reward" (p1).

Rotter (1954) and Rotter, Chance and Phares (1972) postulated that "The I-E dimension is a generalised expectancy that occurs when individuals have learned that events are contingent or non-contingent on their behaviour". It was also stated by them that individuals holding internal expectancies are more likely than externals to take responsibility for their actions and to attribute responsibility to agents who activate change. They also stated that, in performance task situations, internals are perceptually alert and attentive and appear to gather and process information effectively for problem solving.

1.5.3 Support for this model

Since these developments, a number of researchers have drawn attention to the implications for health and illness related areas. Wallston and their colleagues (Wallston et al, 1976; Wallston et al, 1976) for instance found that internals who value their health are more likely than others to select and gather information about disease and health maintenance when alerted to possible hazards, such as

hypertension. Weaver (1972) reported in their work that internal patients with severe kidney disorders, who were dialysing, complied more significantly with dietary restrictions and keeping to appointments than externals.

Bulman and Wortman (1977) found that among severe accident victims more effective coping and better adaptation to long term disability were found with individuals with internal locus of control than with externals. Lefcourt (1980) reported that in illness situations, an internal locus of control variable held a better prognosis, when it came to coping with physical and psychological difficulties associated with an illness, than an external locus of control variable.

An issue throughout the I-E variable and maladaptive behaviour is the aspect of externality and depression. Studies by Lefcourt (1967); Phares, Ritchie and Davis (1968); Rotter et al (1965), and Strickland (1970) strongly support the hypotheses that persons with an internal locus of control "(a) are more alert to those aspects of the environment which provide useful information for their future behaviour, (b) take steps to improve their environmental condition, (c) place greater value on skill or achievement reinforcement and are generally more concerned with their ability, particularly their failures, and (d) are resistant to subtle attempts to influence them" (Rotter, 1966, p.25). Consequently, they are in a much better position to cope with their problems.

In contrast to the above hypotheses, studies by Du Cette and Wolk (1972) and Gurin, Gurin, Lao and Beattie (1969) provide a different perspective. The above hypotheses, these authors say presume that internal beliefs represent positive confirmation and external beliefs negative confirmation. DuCette et al and Gurin et al's studies argue that an external locus of control has positive aspects such as a more liberating attitude to interpersonal and other relationships, a

greater tolerance of chaotic and unpredictable situations, more realistic appraisal of the nature of what influences humans, and a less overt desire for power (Janzen & Beeken, 1973). These findings, however, were not adequately supported by research and therefore were not considered to be the prevailing opinion.

Theorists such as Nowicki and Strickland (1973), Lefcourt (1967), Miller (1970), Penk (1969), Phares et al (1968), Bailer (1961) and Piaget (1975) postulated that locus of control can be affected by life experience. They state that persons with an internal locus of control attempt to take action and confront situations in order to control the outcome. Miller (1970) and Phares et al (1968) gave an example of a situation whereby when three persons were told that they had personality deficiency, persons with an internal orientation appeared more open to remedial programmes. Dua's (1970) research, for example, showed that persons with an external locus of control can move along the internal-external continuation toward internality when taught new behaviours for dealing with situations of interpersonal anxiety. Studies by Masters (1970) and Nowicki & Barnes (1973) further emphasised this notion that a person's perception of control can be altered in the direction of internality.

There are other studies which show support for individual components of the model.described Mischel, Padilla, Grant and Sorenson's (1991) study was on women who were undergoing treatment for gynaecological cancer and the focus on positive problem focused coping ideas and an opportunity to look at appraisals of the individuals. Smith & Wallston's (1992) study of Rheumatoid Arthritis patients provides an understanding of the adaptation to Rheumatoid Arthritis, especially the variables likely to prove important to understanding the processes leading to relatively good or relatively poor adaptation. This type of

coping can best also be described by the idea of the locus of control discussed above.

Rosenstiel and Keefe (1983) postulated in their study of chronic low back pain (CLBP) that individuals with CLBP who have coping styles characterised by passivity, avoidance, or excessive negativity show heightened levels of depressive symptomatology. Similar findings have been reported in non-disabled populations where individuals who use more passive or avoidance coping strategies experience higher levels of emotional distress than individuals who do not use these strategies (Billings and Moos, 1981; Coyne and Gotlib, 1983; Holahan and Moos, 1985).

1.6 Psychological Therapies and MS Coping

It has so far been established from the literature review that MS is a disease with varying degrees of disability, having profound psychological consequences such as anxiety, depression, low self-esteem, and possibly poor self-image (Vander-Plate, 1984). Therefore, intervention is of paramount consideration in helping individuals manage to cope with the emotional features.

1.6.1 Research

1.6.1 (a) Overview

The literature search on psychological intervention in MS primarily comprises Case Reports (Minden, 1992), and controlled and uncontrolled studies. The uncontrolled studies are varied. These include group studies of psychodynamic

therapy (Day, Day and Herman, 1953), psychoeducational programmes (Barnes, Busse and Dinkin, 1954), hypnotherapy (Brunn, 1966), support (Hamburg and Adams, 1967), and biofeedback (La Riccia, Katz, Peters, Atkinson and Weiss, 1985).

Controlled studies are also varied and few. Crawford and McIvor's (1985) study on long-term psychodynamic group therapy, Larcome and Wilson's (1984) short-term group cognitive behavioural treatment approaches, Foley, Bedell, La Rocca, Scheinberg and Reznikoff's (1987) stress innoculation training in coping with Multiple Sclerosis, and Schwartz and Rogers (1994) psychosocial intervention approaches, are the prominent research areas of psychological intervention in MS. An example of each of the approaches will be discussed.

1.6.2 Case Report

Minden's (1992) case studies attempted to identify the common psychological and social difficulties experienced by people with Multiple Sclerosis. Minden raised questions about how these difficulties may be related to the particular characteristics of the MS disease. The author attempted to ascertain the specific psychiatric disorders that occur most frequently among this group of patients, delineate some distinctive themes that regularly arise in the course of psychotherapy with people with MS, and finally discuss various technical issues that are relevant to psychotherapy. By psychotherapy the author meant "a treatment of mental disorder and problems in living that relies on the relationship between patient and therapist to help the patient achieve greater understanding of his or her failings, wishes and beliefs and as a result, enabling him/her to exercise more control over his/her life, ideally achieving more satisfactory relationships and less emotional pain". (Minden, 1992, p198.)

Minden's study discussed these issues mentioned above by identifying and illustrating case histories. Her main aim of the paper was to highlight the importance of making the patient become aware of psychotherapy procedures rather than evaluations of the procedures of psychotherapy.

1.6.3 Uncontrolled Studies

Day et al (1953) reported on the use of psychotherapy in MS. The focus of this paper was the effect of patients' feelings on their social interaction. They reported on how mixed feelings were addressed by MS patients, particularly towards their illness, mood, and their social interpersonal functioning. An analytically orientated group therapy approach was adopted. They selected 23 patients from the 200 available on the roster of the Multiple Sclerosis Research Clinic. The criteria of selection were unspecified. The drop-out rate was reported to be high. Of the 23 canvassed, only 5 females and 2 males attended an average of 50 sessions of one and a half hours, each on a weekly basis. Day et al identified the various methods the subjects used to handle painful issues. The methods most commonly used were denial and this was considered as being "good"; somatic complaints, scapegoating, and projection were other commonly used approaches. They also reported the secondary gains from the illness such as the tacit acceptance of a dependent position which was socially rationalizable and personally acceptable. Although these are valid observations, the authors failed to report their method of evaluation. In addition, the sample is small, biased and unrepresentative of the MS population. Hitherto, generalisation of their findings is difficult.

Barnes et al's (1954) study again reported on psychotherapy approaches with MS patients. The prime goal of their study was to help patients reduce their dependence on the physical medicine department and improve interpersonal adjustments and reduction in their anxiety towards their illness by the use of psychotherapy methods. Barnes et al's study involved 6 MS patients. Subjects chosen were significantly neurologically impaired with mobility problems but with no evidence of psychiatric problems. These individuals were assessed using the Wechsler Bellevue Intelligence Test and Rorschach Test. Although all patients demonstrated some depressive tendencies, none showed any evidence of euphoria.

Barnes et al acknowledged that it was difficult to characterise the type of psychotherapy used in their study. The group leader was a physician. The group programme lasted approximately 6 months. The authors were unable to provide quantitative evaluation of their data, as there were no assessment measures used but their impression was that patients were considerably less anxious and depressed than at the beginning of therapy. At a two year follow-up, they stated that one patient returned for physical therapy irregularly, two patients from the group married each other, two patients did not come in for any treatment, and one patient was subjected to complication of illness 8 months prior to the two years' follow-up. Again generalisation of their finding is difficult.

Brunn (1966) presented a case report to highlight the role of hypnosis in the management of MS. Brunn's subject was a 46 year old female, and the author studied her since 1946. The procedure was administered to allay the patient's fear and distress in order that the patient could co-operate more easily with the medical and nursing care. It was found that with the use of hypnotic

techniques, the patient was able to achieve somnambulistic trance rapidly upon being given a simple cue. This was eventually to be utilised post-hypnotically in order to reduce spasticity so that the patient could flex her knees for the purpose of sitting in her wheelchair. Generalisation of these cues was also reported to the point of enabling the patient to be medically examined.

Brunn emphasised that hypnosis is not a cure for neurological diseases such as MS, but it may be of value in reducing fear and tension and other symptomatology in these patients. It was also stated that it may be helpful in enabling the patients to co-operate more effectively in their medical and nursing care.

La Riccia et al's (1985) case report is another example of this type of approach. They used biofeedback and hypnosis with an MS patient who was being weaned off the mechanical ventilator. The patient they reported was a 30 year old woman with respiratory failure, secondary to MS. She was given 8 sessions of biofeedback over a 12 day period in which the movements of her chest wall were displayed on an oscilloscope. These sessions also included hypnosis in which the patient was given a suggestion of well-being and that she could breathe as she had had before her breathing problem began. Following this the patient was successfully weaned off the mechanical ventilators.

1.6.4 Controlled Studies

Crawford et al (1985) studied the relationship between insight-orientated group psychotherapy and the psychological adjustment of patients with the primary diagnosis of MS. They postulated that addressing these issues would decrease the levels of anxiety and depression and at the same time would increase the

sufferer's self-concept and self-direction. They screened 41 in-patients with the primary diagnosis of MS and chose 32 subjects who had mild to moderate deficits in mental status. The Minnesota Multi-Phasic Personality Inventory (MMPI) Depression - 30 Scale (D30), the Institute for Personality and Ability Testing (IPAT), the Anxiety Scale Questionnaire (ASQ), Nowicki - Strickland Internal External Scale and Rosenberg Self-Esteem Scale were used as assessment tools with their group of subjects. These subjects were then matched into triads on the basis of gender, pre-test scores, and length of illness. Each member of the triad was then randomly assigned to one of three groups: 1) traditional insight-orientated psychotherapy group, 2) current events discussion group, 3) non-treatment or control group. Except for the control group the two other groups met twice weekly for one hour for 50 sessions. All patients were re-assessed after 50 sessions. The authors stated that the insight-orientated psychotherapy group was significantly less depressed compared to the other two groups. The psychotherapy and current events groups were significantly more internally orientated than the control group on post-hoc comparison. There was no significant difference noted for either anxiety or self-esteem. They concluded group methods to be a viable therapeutic approach for MS patients and group psychotherapy to yield significant gains. The authors acknowledged that the sample size is small, which can be considered as one of the limitations of the study. Another issue worth noting is the use of a combined approach that is psychotherapy along with a direct approach may have yielded a more desirable outcome, especially from the point of view of the reduction of anxiety and improving self-esteem.

Larcombe et al (1984) evaluated cognitive behaviour therapy for depression in in-patients with MS. They studied 20 depressed MS patients whom they randomly selected through an MS Community Centre and through a General

Hospital which specialised in treatment for this disorder. Only individuals who met with their 10 selection criteria were included in the study. Their criteria were: 1) subjects between the ages of 20 and 65, 2) a diagnosis of MS by a Neurologist, 3) a self-reported duration of depression of at least 3 months, 4) not receiving concurrent or prior treatment with major tranquillisers, 5) score of at least 20 on the Beck Depression Inventory, 6) fullfilment of research criteria for 'definite' or 'probable' depression according to the Feighner et al's (1972) critera, 7) low suicidal risk, 8) absence of other major psychological disorders, 9) score within normal range on a revised version of the paired associate learning subtest of the Wechsler Memory Test, and 10) willingness to participate in a treatment research project.

Larcombe et al used these strict criteria in order to obtain an MS sample for whom depression was a major psychological problem. The potential subjects were screened in two stages, initial background screening by mail, and subsequently subjects who met the criteria 1 - 4 were interviewed in person.

The authors initially sent questionnaires to 54 subjects. Only one failed to return the questionnaire. Twenty-one subjects met all the criteria on the first stage of screening and one subject failed to meet the criteria in the second stage of screening. One discontinued treatment after one session, therefore 19 subjects constituted the sample size.

These subjects were then randomly allocated into either cognitive behaviour therapy or waiting list conditions. Subjects allocated to the therapy conditions received weekly one and a half hour sessions of treatment for 6 weeks, in a group format. The waiting list subjects were informed that due to limited

facilities, their treatment would be delayed for 6 weeks and they would be treated at the end of that time.

The results highlighted that subjects in the therapy conditions improved significantly more than subjects in the waiting list conditions. The waiting list group also subsequently completed treatment and eventually improved. Larcombe et al found that both these groups maintained their improvement at one month follow-up.

Although this study is a well-controlled study, there are a few comments worth making, relating particularly to the lack of control for placebo or non-specific therapy factors such as group support, therapist attention, and involvement in a therapy programme. Questions such as whether or not the actual elements of therapy (e.g., increase in activities and modification of cognitions) were responsible for the observed changes, or whether non-specific factors such as attention and the opportunity for social interactions accounted for the outcome were not investigated. This is an important consideration in view of the fact that some researchers have suggested that depression in MS may be essentially a result of biochemical changes brought by the disease itself renders this consideration important. The other comment about Larcombe et al's study is that the follow-up period of one month is too short for generalisation to be made.

Foley et al's (1987) study examined the efficacy of stress innoculation training (SIT) in coping with MS. The SIT is one approach which is said to increase psychological symptom control (Michenbaum, 1977). It is a short-term psychotherapeutic intervention that attempts to improve coping by decreasing

emotional distress and by preventing maladaptive psychological response to stress.

Foley et al reported that theirs is the first controlled study of an individual psychological treatment approach in MS. This study is said also to measure disease variables that could easily confuse outcome findings such as disease duration, severity and current exacerbation status. In addition they stated that their study assessed the coping outcomes such as psychological distress covering the areas of depression and anxiety and mediators such as locus of control and trait anxiety.

Thirty MS out-patients took part in this study. Individuals with a confirmed MS diagnosis, a level of disability not exceeding 8 on the 10 point Disability Status Scale, and no major cognitive deficits were considered for this study. The 36 subjects who took part in this study were randomly assigned to either the SIT programme or a current available care (CAC) programme, which constituted the control condition. The SIT programme consisted of a six session cognitive behavioural procedure including a shortened version of progressive deep muscle relaxation. These subjects were assessed following completion of the SIT programme and the CAC patients received a variety of psychotherapeutic and medical intervention during their waiting period. All CAC patients received a minimum of two hours of supportive psychotherapy, two subjects from this group received anti-depressive therapy, another two family counselling and three others individual counselling. This group of patients was re-tested 5 weeks after the CAC period.

Foley et al reported a significant improvement at post-treatment for SIT subjects in depression, state anxiety, coping with daily stresses, and problem-focused

coping efforts compared to CAC treatment. There was no significant difference found between the groups with regard to disease severity and current disease activity.

A six month follow-up evaluation demonstrated that the improvement was maintained, although only 50% of the experimental group participated in this evaluation due to "unavoidable circumstances".

They concluded that a brief programme such as SIT can significantly assist patients with chronic illness to cope more effectively with subjective stress. A comment worth making here is that this study did not control for the intervention time, which may have influenced the outcome in view of the remitting/relapsing nature of MS.

The Psychosocial Intervention Approach is another approach that has been used widely in the management of psychological difficulties arising from neurological disabilities. In this type of approach the main theme is "effective coping". This is achieved by learning flexibility. Flexibility is defined by Schwartz (1990) as the ability to recognise when what one is doing is not working then to move in a purposeful manner to new methods by trial and error approaches. This type of approach Schwartz stated "involves the individual being aware of the repertoire of coping strategies along with perceiving the options available, that is, being able to shift in a purposeful trial and error manner to new approaches." (Schwartz, 1990). This type of approach is said to lead to a sense of control over the area of one's life that are possible to control. For example, for people suffering from MS, a disease characterised by variability and uncertainty, attempting to control their health is likely to result in failure and consequently a sense of helplessness (Wortman and Brehm, 1975).

Schwartz and Rogers (1994) suggested that people with MS need to exert control over their domains of their life such as developing hobbies and engaging in work and social activities in order to have a better quality of life. As a result of this control, they state that a positive feedback loop will develop which will then lead to improved coping, thereby instilling confidence in one's ability to manage symptoms relevant to the disease. The authors refer to this type of coping as self-efficacy.

One self-efficacy theorist, (Bandura, 1977, 1982) has proposed that all forms of psychotherapy and behavioural change operate through a common mechanism: the alteration of the individual's expectations of personal mastery and success. According to this concept, two types of expectancies exert powerful influences on behaviour - a) the belief that certain behaviours will lead to certain outcomes, and b) the belief that one can successfully perform the behaviour in question (Scheier et al, 1982).

Basing on this concept, Schwartz et al (1994) stated that "the process of teaching coping flexibility should involve helping participants when their coping efforts are not effective, to differentiate controllable domains from uncontrollable ones and to become aware of other options or perspectives and thus other possibilities for action" (p58). This is said to lead to the development of self-awareness, acknowledgement of the strengths and weaknesses one possesses and to become familiar with one's assets and deficits.

Schwartz et al (1994) carried out a study in the aspect of social intervention; the process consisted of 8 two hour sessions. These sessions were time-limited sessions and the contents were of a supportive and educational nature.

Each of the their sessions began with a brief relaxation session to create a quiet calm mood for the individuals for learning, and the sessions closed with a discussion on how relaxation reflects coping flexibility. Some of the sessions included assignments of homework for the following week. That was intended to stimulate thinking about the topic on the next weeks' agenda. The intervention agenda was as follows: introduction of group members, dealing with feelings, discussions on images of illness, goal-setting, coping with cognitive problems, support sessions for care givers and review on the impact of intervention and the changes encountered. The sessions were divided into process, goals, and assignments. At the end of the seventh session each patient was given an unrelated assignment to rank a few people in the group whom they would be willing to contact by telephone on a monthly basis. Coping partners were then assigned at the final session by the group leader, who were expected to call each other monthly to help troubleshoot and to provide an alternative perspective on new problems that may have arisen in the preceding months. This type of intervention Schwartz et al have found to be effective in alleviating some psychological and physiological problems. The authors are said to be currently in the process of evaluating this intervention formally, and the result is to be available in three years from 1994.

1.6.5 Conclusion

Early studies in the area of psychological intervention in MS concentrated on traditional psychotherapy approaches such as Barnes et al's (1954) work and Day et al's (1953) studies. These approaches probably were inappropriate for all but a few individuals with MS but formed an important component in disease management. However, these studies reported intervention in only the most

general terms with the exclusion of support. Furthermore, no evaluative outcome results were reported in these studies.

Research studies in the areas of psychological intervention in the 1980's adopted a different approach, incorporating the importance of support, perception and coping. As a result of these views cognitive therapy approaches, Stress Innoculation Training approaches and the Psychosocial Intervention approaches have become more prevalent in the management and coping of MS, as was shown by Foley et al (1987), Larcome et al (1984) and Schwartz et al's (1994) work. It can also be said that these studies have been evaluated.

1.7 Present Research

The goal of this study is to develop a measure of perception of coping for use with progressive illness. The rationale for developing such a measure is first to produce a tool that would provide more sensitive predictions of the relationship between internality and coping; in addition it is hoped that this scale can generally be used with those who suffer from other chronic diseases such as chronic pain. Literature search in this area highlighted various measures. These include measures that focus on preventative and recovery aspects of health and disease. Wallston et al (1987) discussed the difficulty of predicting behaviours in a specific area using generalised expectancies such as Rotter's (1966) Internal-External Locus of Control (I-E) Scale. The same can also be said about measures that focus on preventative and recovery locus of control. Besides, Rotter (1975) and Phares (1972) suggested that situation-specific measures should be developed to predict the behaviour of individuals in a particular context.

Secondly, patients with neurological disorders enter rehabilitation with varying degrees of disability and handicap. The questions were raised as to why some individuals with extensive degrees of disability and handicap cope better than perhaps others with lesser problems. Patients who enter therapy enter with differing levels of control and perceptions, hence, a scale such as this may enable therapists to identify this concept and tailor the course and style of therapy. The scale might also provide a useful index of progress in therapy since perception of coping should change during therapy.

2. METHODOLOGY

Prior to starting the study ethical approval was obtained from the ethical committee of Ayrshire and Arran Health Board.

2.1 Part One - The Development of the Scale

2.1.1 Introduction

The aim of this part of the study was to develop a measure of perception of coping based on the theoretical model discussed in chapter one, section 1.5.1.

2.1.2 Population Used

For this part of the study the MS Register kept at the Douglas Grant Rehabilitation Unit at Ayrshire Central Hospital, Irvine, was referred to. The Douglas Grant Rehabilitation Unit is the only Unit within Ayrshire and Arran which provides a rehabilitation service for patients with neurological disorders and acquired brain damage. Patients are referred from across the region of Ayrshire and Arran. The MS Register provides a record of all MS patients who have been in contact with the Unit since it opened in 1990. Thus it does not provide an exhaustive list of all MS sufferers within Ayrshire and Arran.

2.1.3 Subject Selection

40 MS sufferers between the ages of 16 - 64 were randomly selected from the MS register. The following randomisation procedure was adopted: starting with the first patient in the Register every third patient was selected. If any of the

third patients were not between the ages of 16-64 then the subsequent third patient was considered. In this manner the 40 subjects were recruited for the study. They were then contacted by letter and a brief resume of the project was outlined to them as follows:

Dear Mr/Mrs/Ms/Miss

We are undertaking a small research study in the area of MS. Should you wish to take part in this, please contact the Rehabilitation Unit at Ayrshire Central Hospital, either by telephone or by writing.

The procedure will take up an interview form, and the questions will be about your diagnosis, the way you are coping, and your general views on this disease. Your responses will be tape-recorded. From the recording relevant information will be extracted and the tape will be erased. We require no personal details, such as name, age, or address, and we will ensure confidentiality throughout. We will discard the transcripts as soon as we have processed them.

Yours sincerely

.....

Please delete as appropriate.

I (name) ..... wish/do not wish to take part in this study.

A reply slip was appended for return in a pre-paid envelope. All 40 letters were sent out on the same day to ensure that all had the chance of receiving the letter at about the same time. This was to ensure that all subjects had the same amount of time to respond. Thirty-six positive responses were received. Approximately 10% (n=4) failed to return the reply slip. The reason for this failure was not sought. The first 20 replies were considered for the study, and the remaining 16 were used for pilot trial - the details of which will be explained in the procedure section.

2.1.4 Material Used

Three audio cassette recorders were used to record answers to the following questions. These questions were devised from the working model explained in Section 1.5.1 (Figure 1).

A. When were you told you had MS?

B. What effect did this have on you?

C. Have you found out any more about the illness?
(Patient needs to provide a definite answer)

D. What kind of problems are you currently experiencing?
   (i) Physical
   (ii) Emotional
   (iii) Domestic/Social

E. In what ways are you coping or how are you coping?

F. Do you have control over your illness?

G. Can you do anything to gain control over your illness?
   (i) in terms of looking after yourself
   (ii) in terms of work
   (iii) in terms of domestic and social situations

H. Do you have much support and help?
   (i) at home
   (ii) at work
   (iii) outwith both these places

I. In view of your condition, how do you see the future?

J. Can you improve your condition? Is it in your control or outwith your control?

K. What, if anything, can you do to improve your situation?

L. Can you alter the course of your illness?

M. During exacerbation of symptoms, how do you cope?

2.1.5 Procedure

Three assessors were involved in this part of the study, a Consultant Physician, the Superintendant of Physiotherapy, and a Consultant Clinical Psychologist. The questions were carried out in an interview format. Prior to interviewing the 20 subjects, the three assessors carried out pilot interviews with the 16 subjects who agreed to take part in the study but were not considered for this part of the study. The pilot procedure was carried out in order to ensure uniformity of the interviewing procedure by the three assessors. Once the style of interview was established the three assessors interviewed the 20 chosen subjects. The interview responses were tape-recorded and transcribed and the tape recordings were erased to ensure confidentiality. Content analysis was carried out on the transcripts; i.e., all descriptive phrases and words used by subjects were extracted for each question, as shown below.

1. **What effect did the diagnosis have on you?**

Devastating	None
Distress	No effect
Shock	Acceptance
Life had ended	Anger
Upset	Relieved
Sorry	Positive
Bitter	

2. **Have you found out any more about the illness?**

Yes

Reading about it

Watching television documentaries

Talking to others with the same problems

Attending self help support groups

Attending the rehabilitation unit

Speaking to therapists/professionals

I try not to talk about it

I try not to find out

3. **What kind of problems are you currently experiencing?**

Tiredness	Weakness	Hate
Tremor	Balance	Being fed up
Mobility	ADL	Being incomplete
Co-ordination	Depression	Anxiety
Tearful	Low mood	I just get on
Frustration	Anger	Wheelchair bound
Changeable mood	Problems with support from family and friends	
High dependency	I only think about it sometimes	
Housebound	I have no problems	
Embarrassment		

4. **In what ways are you coping? How are you coping?**

Dependency on others/family
Taking it one day at a time
Relaxing
Attending the Rehab Unit and therapies
Coming to terms with the diagnosis
Not coping as well as I should
Avoiding stress
Balancing the days activities

5. **Do you have control over your illness?**

Yes No Sometimes

6. **What can you do to have control over your illness?**

Control by way of drugs
Help from family
Accepting my disease
Not been in control despite trying the advice
The illness controls me
Doctors assurance
Mind over matter
Positive thinking
Never been in control

7. **Do you have much support and help?**

Yes No Sometimes

At home At work Family and friends

Therapists and medical professionals are supportive

Support from Social Services

Most people are supportive

8. **In view of your condition, how do you see the future?**

Worse Hope Bleak Cure Frightening
Better Pessimistic Bright Difficult to say
Down-hearted Optimistic

9. **Can you improve your condition?**

Yes No Sometimes
Rearrange environment Diet Slow down
Exercise Take advice Keeping cheerful
Improving faith Compromising Keep busy
Continue as normal You can't change the condition

10. **During exacerbation of symptoms how do you cope?**

Lie back Fight it Sleep Ignore it Ease off Steroids
"Let's do something about it" Frightened Depressed
Can't handle It's just another hurdle
"This is the end" Adjust behaviour

11. **Can you alter the course of your illness?**

Yes No Sometimes No control Diet Fight it
I don't think I can Think positive I would like to think I have
I don't know Mind over matter Relax more

These phrases and words were then presented to 10 judges. The 10 judges were made up of two psychiatrists, two clinical psychologists, two rehabilitation physiotherapists, two rehabilitation occupational therapists, and two rehabilitation physicians. The 10 judges were instructed to rate the statements

into 3 categories - internal statements, external statements and neutral statements The definition for these three concepts was given prior to the categorisation of these statements. The definitions provided were: internal statements are those that the subjects reported having some control over, external statements are those that the subjects reported a lack of control over, and neutral statements are those that did not fit into any of these two categories. Details of the categorisation are presented below.

	Judges										**Total Res.**
Have you found out any more about the illness?	1	2	3	4	5	6	7	8	9	10	
Yes	I	I	I	I	I	I	I	I	I	I	
No	E	E	E	E	E	E	E	E	E	E	
Reading about it	I	I	I	I	I	I	I	I	I	I	*
Watching television documentaries	I	I	N	I	I	E	I	E	N	I	
Talking to others with the same problem	I	I	I	E	E	I	I	E	I	I	
Attending self-help support groups	I	I	I	I	I	I	I	I	I	I	*
Attending the Rehabilitation Unit	N	I	N	E	E	N	I	E	I	N	
Speaking to therapists/professionals	N	N	N	E	E	E	I	E	I	I	
I try not to talk about it	I	I	E	N	N	I	E	I	E	E	
I try not to find out	I	I	E	N	N	I	E	I	E	E	
In what ways are you coping/How are you coping?											
Depending on others/family	E	E	E	E	E	E	E	E	E	E	*
Taking it one day at a time	I	I	N	I	I	I	I	I	I	I	
Relaxing	I	I	N	I	I	I	I	I	I	I	
Attending the Rehab Unit and therapies	N	I	N	E	E	E	I	E	I	N	
Coming to terms with the disease and diagnosis	I	I	I	I	I	I	I	I	I	I	*
Not coping as well as I should	N	N	E	N	N	I	I	I	N	I	
Avoiding stress	E	I	N	I	I	I	I	I	I	I	
Balancing the days activities	I	I	N	I	I	I	I	N	I	I	
Do you have control over your illness?											
Yes	I	I	I	N	N	I	I	I	I	I	
No	E	E	E	N	N	E	E	E	E	E	
Sometimes	N	I	N	N	N	N	N	N	N	N	

	Judges										Total Res.
What can you do to have control over your illness?	1	2	3	4	5	6	7	8	9	10	
Control by way of drugs	E	E	E	E	E	E	E	E	E	E	*
Help from family	E	E	E	E	E	E	E	E	E	E	*
Accepting my disease	I	I	E	I	I	I	E	I	I	I	
Not been in control despite trying the advice	E	E	E	N	N	N	E	E	E	I	
Never been in control	E	E	E	N	N	I	E	E	E	I	
The illness controls me	E	E	E	E	E	E	E	E	E	E	*
Doctors assurance	E	E	N	E	E	E	E	E	E	E	
Mind over matter	I	I	I	I	I	I	I	I	I	I	*
Positive thinking	I	I	I	I	I	I	I	I	I	I	*
In view of your condition, how do you see the future?											
Worse	E		E	I	N	I		E	E	I	
Bleak	I		E	I	N	I		E	E	I	
Frightening	I		E	I	I	I		E	N	I	
Pessimistic	I		E	I	I	I		E	E	I	
Difficult to say	I		N	N	N	I		N	N	I	
Down-hearted	I		E	I	I	I		E	E	I	
Optimistic	I		N	I	I	I		I	I	I	
Hope	I		I	I	I	I		I	I	I	
Cure	E		I	E	E	I		E	E	I	
Better	E		N	I	I	I		I	I	I	
Bright	I		I	I	I	I		I	I	I	
Don't know	N		N	N	N	I		N	N	N	
Can you improve your condition?											
Yes	I	I	I	I	I	I	I	I	I	I	
No	E	N	E	E	E	E	E	E	E	E	
Sometimes	N	I	N	N	N	N	N	N	N	N	
Rearrange environment	I	I	N	E	E	E	I	E	N	I	
Slow down	I	I	I	I	I	I	I	I	I	I	*
Take advice	I	I	N	I	I	E	I	E	I	I	
Improving faith	I	I	N	I	I	I	I	I	N	I	
Keep busy	I	I	I	E	E	I	I	E	I	I	
You can't change the condition	E	I	E	I	I	N	E	N	E	I	
Diet	I	I	I	E	E	E	I	E	I	I	
Exercise	I	I	I	E	E	E	I	E	I	I	
Keeping cheerful	I	I	I	I	I	I	I	I	I	I	*
Compromising	I	I	I	I	I	I	I	I	I	I	*
Continue as normal	I	I	N	N	N	N	E	N	I	I	

	Judges										Total Res.
During exacerbation of symptoms how do you cope?	1	2	3	4	5	6	7	8	9	10	
Lie back	I	I	N	N	N	E	E	E	E	E	
Sleep	I	I	E	N	N	E	I	E	E	I	
Ignore it	E	I	E	I	I	I	E	I	N	I	
Ease off	I	I	N	E	E	E	I	I	I	I	
Steroids	E	E	E	E	E	E	E	E	E	E	*
It's another hurdle	I		N	I	I	I	I	I	I	I	
Adjust behaviour	I	I	N	E	I	E	I	I	I	I	
Fight it	N	I	I	E	I	I	I	I	I	I	
"Let's do something about it"	I	I	I	E	E	I	I	I	I	I	
Frightened	E	N	E	I	I	I	E	E	N	I	
Depressed	E	N	E	I	I	I		I	E	I	
Can't handle	E	N	E	N	N	I		E	E	I	
"This is the end"	E	N	E	I	I	I		E	E	I	
Can you alter the course of your illness?											
Yes	I	I	I	I	I	I	I	I	I	I	
No	E	N	E	E	E	E	E	E	E	E	
Sometimes	N	I	N	N	N	N	N	N	N	N	
No control	E	N	E	N	N	N	E	E	E	E	
I don't think I can	I	N	E	N	N	I	E	E	E	E	
I would like to think I have	I	I	N	I	I	I	I	I	I	I	
I don't know	N	N	N	I	N	N		N	N	N	
Relax more	I	I	N	E	I	E	I	I	I	I	
Diet	I	I	N	E	E	E	I	E	I	I	
Think positive	I	I	I	I	I	I	I	I	I	I	*
Fight it	E	I	I	E	I	I	I	I	I	I	
Mind over matter	I	I	I	I	I	I	I	I	I	I	*

Where there was 100% agreement by the judges, these statements were extracted and made into statements as shown below.

Have you found out any more about the illness?

I. I found out about the illness by reading.

I. I found out about the illness by attending self-help support groups.

In what ways are you coping/How are you coping?

E. I cope with my disease by depending on my family and others.

I. I cope with the disease by coming to terms with it and coping with the diagnosis.

What can you do to have control over your illness?

E. I control my illness by way of drugs.

E. I control my illness by way of receiving help from my family.

E. I hardly have control over my illness, the illness controls me.

I. I employ the 'technique' of mind over matter to help me take control over my illness.

I. I use positive thinking as a way to control the illness.

Can you improve your condition?

I. I improve my condition by way of keeping cheerful.

I. I compromise to allow improvement in my condition.

During exacerbation of symptoms, how do you cope?

E. During exacerbation of symptoms I use steroids.

Can you alter the course of your illness?

I. I can alter the course of my illness by thinking positively.

I. I can alter the course of my illness by using the technique of mind over matter.

From these statements the scale was developed and a title was provided as shown below.

CHRONIC ILLNESS

PERCEPTION OF CONTROL (PC) SCALE

This scale will help us to find out about how you are managing your disease at present.. Read each statement and underline the response which comes closest to how you have felt in the last week or so. Don't take too long over your replies, your immediate reaction will probably be more accurate than a long, thought-out response.

Thank you very much for completing this scale.

1. Finding out about this disease will help me manage my symptoms.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
2. Coming to terms with the diagnosis and the disease will make all the difference in coping with my illness.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
3. Being in control of my illness depends on my individual effort.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
4. Positive thinking plays an important part in controlling my illness.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
5. Keeping myself cheerful helps me to control my illness.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
6. Finding a "happy medium" or "striking a balance" allows for improvement in my coping with the illness.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
7. The course of my illness can be altered by way of thinking positively.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
8. Mental strategies such as "mind over matter" help alter the course of my illness.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
9. I cope with the disease by depending on assistance from other people.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
10. I have little or no control over my illness.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
11. Drugs are the only agent that enables me to cope with my exacerbation of symptoms	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly

The scale comprises of 11 statements. Each statement has 5 possible responses ranging from agree strongly to disagree strongly. The scoring ranged from +2 through to -2; agree strongly was rated as +2; agree slightly as +1; neutral as 0; disagree slightly as -1 and disagree strongly as -2 for items 1 to 8. The score is then reversed for items 9 to 11, i.e., agree strongly was rated as -2 to disagree strongly as +2. It is expected that those who have external perception of the disease will score negatively from those who are internal in their perception of the disease. Readability tests were carried out to ascertain the reading ease of the scale. Using the Corporate Voice Computer Package the Flesch Reading Ease Index and the Gunning Fog Index were calculated. The Flesch Reading Ease Index was calculated to be 65.7. This means that approximately 75% of the population should be able to understand the text. The Gunning Fog index was calculated to be 7.3. This means the material would be suitable for people with a reading age of 12-13 years.

2.2 Part Two - Validation of the Scale

2.2.1 Introduction

The aim of this part of the study is to validate the devised scale, i.e., the Perception of Control Scale (PCS) and to ascertain if this scale measures and identifies what it was intended to measure, ie, perception of coping.

2.2.2 Population Used

Multiple Sclerosis (MS) out-patients referred to the Douglas Grant Rehabilitation Unit for a conventional rehabilitation programme were considered for this part of the study. As mentioned previously patients attend the Unit from the whole region of Ayrshire and Arran.

2.2.3 Subject Selection

20 MS patients referred for conventional rehabilitation programme (CRP) were considered for this study. None of these 20 subjects was involved in the first part of the study. CRP in this case is the programme provided by the Physiotherapy Department. The subjects were aged 16 and over and were fluent speakers of English. The subjects were recruited during their first visit to the Rehabilitation Unit. The receiving physician introduced the study by providing the following verbatim outline:

"we in the Unit are carrying out a small research study looking at patients views on their illness and the way they feel they are coping. The procedure will involve you giving some basic information about yourself. Your name and address are not necessary and you will be required to complete some measures. Once your rehabilitation programme is over you will be asked once again to complete a new set of the same measures. All information will be dealt with confidentially".

If the patients agreed to take part in the study they were then referred on to the independent interviewer . The independent interviewer was a graduate Psychologist who was familiar with the psychological processes involved and was able to discuss the individual's problem if the patient chose to do so. The reason for choosing an independent interviewer was to ensure that the scale was completed objectively without experimenter bias. The interviewer once again explained the participation involved in the study by providing the same verbatim outline as the receiving physician. The subjects were given the opportunity to decide whether they wished to take part in the study or not. Those who wished to take part in the study were then seen by the interviewer.

2.2.4 Measures: The following measures were used -

(i) Demographic information
(ii) GHQ 28 item
(ii) HAD Scale
(iii) COPE Scale
(iv) The currently developed Perceived Control Scale

2.2.4 (i) Demographic Information

The following information was deemed important in order to ascertain some basic information about the subjects and the nature of their illness. This was administered at the initial interview.

Date of assessment
Date of birth
Sex M/F
Marital status: M/S/D/Sep/Widowed

Do you live alone?

In which year was the diagnosis made?

Current medication (over the last month):

What is your current problem that brought you to this Unit?

Medical/Mobility/Emotional/ADL

2.2.4 (ii) General Health Questionnaire (GHQ) 28 items (Goldberg, 1978)

The GHQ is a self administered screening test aimed at detecting those forms of psychiatric disorders common among respondants in community settings, such as primary care or among general medical out-patients (Goldberg, 1972). The GHQ consists of a list of symptoms and the subject is required to indicate to what degree s/he has been affected by each one of the symptoms over the last few weeks by answering either 'not at all', 'no more than usual', 'rather more than usual' or 'much more than usual'. The basic assumption of this questionnaire is that non-psychotic illness is continuously distributed among the population. The questionnaire therefore does not assign an individual to a category of a 'psychiatric case' or 'non case' but is a screening instrument to identify 'potential cases', leaving the tasks of identifying 'actual cases' to psychiatric interview. It does not cover the whole range of psychiatric illness but was devised to identify those sub-clinically disturbed; it therefore differs from most other questionnaires which divide the population into 'cases' and 'normals'. Its focus is on psychological component of ill health. There are 4 versions to this Questionnaire - the 60-item; 30-item; 28-item and the 20-item Questionnaires. For the present study, the GHQ 28-item will be used for the following reasons: it has a high validity score of 95.7% for sensitivity and 87.8% for specificity (Goldberg, 1970); the shorter version has the advantage of being potentially more acceptable to patients and can be filled in within 5 minutes.

The 28 item scale is divided into four subscales. All the subscales consist of 7 items. GHQA items measured somatic symptoms of psychiatric origin, GHQB measured anxiety/depression, GHQC measured social dysfunction and GHQD severe depression. A copy of this scale is attached in appendix 1.

2.2.4 (iii) Hospital Anxiety and Depression Scale (HAD) (Zigmund and Snaith, 1983)

This is a self assessment rating scale which was designed to minimise the influence of associated physical illness and detect states of depression and anxiety in the setting of a hospital medical out-patients clinic (non psychiatric hospital departments). The scale has been identified as a valid measure of the severity of disorders of mood and therefore a repeated administration of the scale at subsequent visits will give the physician useful information concerning progress.

The HAD can be completed in a short space of time. The scale comprises 7 depression and 7 anxiety items, with four choice responses for each. Each item is thus scored 0-3 with 3 being indicative of maximum symptomatology. Cut off scores are provided as follows: a score of 7 and less as non caseness, a score of 8 to 11 as borderline caseness and a score of 12-21 as definite caseness. The correlation for the anxiety items ranged from + 0.76 to + 0.41 ($p < 0.01$) and for the depression items + 0.60 to + 0.30, ($p< 0.02$). A copy of the scale is attached in appendix 2.

2.2.4 (iv) COPE Scale (Carver, Sheier, & Weintraub, 1989)

This is a multidimensional 60-item coping inventory, developed to assess the different ways in which people respond to stress. The COPE is made up of 15 sub-scales as shown below:

1. Active coping
2. Planning
3. Seeking instrumental social support
4. Seeking emotional social support
5. Suppression of competing activities
6. Religion
7. Positive reinterpretation and growth
8. Restraint coping
9. Acceptance
10. Focus on and venting of emotions
11. Denial
12. Mental disengagement
13. Behavioural disengagement
14. Alcohol/drug use
15. Humour

Scales 1,2,5,7, and 8 measure tendencies that are adaptive in circumstances in which active coping efforts yield good outcomes. Scales 3,4, and 6 measure tendencies that are less explicitly associated with active coping. Scales 10,11, and 12 measure tendencies that should be maladaptive in circumstances in which active coping efforts are necessary to yield good outcomes. Scale 9 measures a tendency that is less explicitly dysfunctional.

The scale items can be used in 3 different formats: (a) a "trait like" version, (b) a time limited version in which respondants indicate the degree to which they actually did use each of the coping strategies during a period in the past. For the purpose of this Study the third version (c) will be used, in which

respondants indicate the degree to which they have been using each of the strategies during a period up to the present. Each item can have one of 4 possible responses (1 = I usually don't do this at all; 2 = I usually do this a little bit; 3 = I usually do this a medium amount; 4 = I usually do this a lot).

The reasons for chosing the COPE Scale are because it assesses a range of responses from aspects of problem focused coping such as active coping and planning, to the use of social supports, to turning to religion as a coping device, to positive framing of the situation, to aspects of avoidance coping such as denial and behavioural disengagement. Also, the internal reliability of the Scale is adequate (alphas averaged across the administration ranged from 0.65 to 0.90.). A copy of the scale is attached in Appendix 3.

2.2.5 Procedure

This part of the study was conducted as a series of interviews by the interviewer, ie, reading the items in the scales loudly and collecting oral responses. One of the physical symptoms of MS is visual impairment, therefore, a decision to read out the scale was taken at the start of the research to keep a uniformity of procedure. There is a possibility that reading out the scales may given rise to a different outcome and the author has taken this on board. In the absence of published reports on this issue Snaith R.P., one of the authors of the HAD scale was contacted by telephone. Snaith R.P., in his personal communication (18th December, 1997), stated that he did not know of any published reports to address this issue and pointed out that the adopted approach, in his opinion could not have a major impact on the outcome. He continued to state that the raised issue was a mere technicality. The author of this study is awaiting written communication from Snaith R.P. to this effect.

The issue regarding the reading out of the scale is an important one and research is needed to establish this.

Following recruitment of the subjects an initial interview incorporating demographic information along with the measures mentioned in section 2.2.4 above were completed.

This interview was designed to take place on the day before rehabilitation programmes began.

The post-rehabilitation interview took place approximately a week after CRP was completed. The interview entailed the re-administration of the measures during the initial interview.

2.2.6 CRP

This programme involved initially one senior physiotherapist assessing the mobility problems presented by the subjects using physiotherapy measurement tools. There after these patients were allocated to one of two physiotherapists who planned and taught graded exercise programmes. This is an individually tailored programme. The emphasis of this programme was to help patients set their own realistic goals for exercise; pace themselves and reinforce the gains of planned exercises to build their confidence and increase their every day activity. Those who came in for medically related problems were seen by the physician who adopted a drug therapy regime.

3. RESULTS

3.1 Introduction

The results of the first part of the research are integrated within the methodology of the study. This chapter will concentrate on the results obtained from the second part of the study, i.e., assessing the reliability, validity and the sensitivity of the Perception of Coping Scale (PCS) with other scales.

3.2 Overview

Details will be provided on the demographic profile of the subjects. Descriptive statistical information on the PCS items will be provided initially followed by Reliability, Construct Validity, and sensitivity of the PCS to change such as the impact of intervention will be specified. The construct validity of the PCS was attempted by correlating the HAD-D, HAD-A, GHQ and COPE total scores. The ability of the PCS to detect the presence of anxiety (HAD-A), depression (HAD-D) and psychiatric caseness (GHQ) will be identified in addition to the ways of coping (COPE).

Comparison of means test (paired t-test repeated measures design) to identify pre and post intervention outcomes on all the scales will be provided. Chi-square tests will be carried out where necessary to compare observed frequencies.

The analyses were carried out using the Statistical Package for Social Sciences (SPSS) in the Windows programme version.

3.3 Demographic Information

(i) *Sex and age distribution*

Table 1 Age and sex distribution

Gender	Mean	SD	Minimum age	Maximum age	Total
Females	40.95	11.87	29	62	11 (55%)
Males	40.89	7.82	32	54	9 (45%)
Overall	40.95	10.00	29	62	20 (100%)

Table 1 shows the details of sex and age distribution. There were 11 women (55%) and 9 men (45%) in this group, roughly equal numbers of each gender. The chi-square test was carried out; the obtained value was 0.2, and the critical value was 3.84 ($P<0.05$ two tailed). Therefore the proportions of males and females did not differ significantly. The overall mean age of the subjects was 40.95 years. The ages ranged from a minimum of 29 years to a maximum of 62 years. For the female subjects the mean age was 41 years and the standard deviation was 11.87 years. These ages are not significantly different between the genders.

(ii) *Marital status and gender analysis*

Table 2 Marital status, and gender

	Gender		Total
Marital Status	Female	Male	
Married	6 (30%)	7 (35%)	13 (65%)
Single	3 (15%)	1 (5%)	4 (20%)
Widowed	1 (5%)	-	1 (5%)
Divorced	1 (5%)	1 (5%)	2 (10%)
Total	11 (55%)	9 (45%)	20 (100%)

Table 2 shows that 65% of the subjects (N=13) were married. 20% of the subjects were single (N=4) while 10% were divorced (N=2) and five percent were widowed (N=1). Of the 13 people married, six were women and seven men. In the single group there were three women and one man. One woman was widowed, and one man and one woman divorced. From a total of 20 subjects only four subjects (20%) reported to living on their own, and the remaining 16 subjects (80%) had someone living with them.

(iii) *Length of Diagnosis of Multiple Sclerosis*

The length of diagnosis ranged from one year to 27 years. The mean number of years of diagnosis was 7.20 years, and the standard deviation was 7.42 years.

(iv) *Problems experienced by subjects at the start of the study*

Table 3 Current problems

Problems	Males	Females	Total
Medical	1	0	1 (5%)
Mobility	7	7	14 (70%)
Emotional	0	1	1 (5%)
Medical & Mobility	1	2	3 (15%)
Mobility & Emotional	0	1	1 (5%)
Total	9	11	20 (100%)

14 subjects (70%) presented with problems of mobility while three (15%) with problems of mobility and medical problems arising from their MS condition (Table 3). One subject (5%) presented with medical problem alone. One (5%) presented with emotional problem, and another one (5%) with mobility and emotional problems.

(v) *Medication at the start of the study*

11 (55%) of the subjects were found to be on some form of medication for their condition at the time of the initial interview. The medication was either painkillers or steroids. There was a reduction in this, following physiotherapy/medical interventions. Five subjects (25%) reported that they had stopped taking their painkillers/steroids.

3.4 PCS - descriptive (item) information, frequency distribution, reliability analyses and inter-item correlation

3.4.1 PCS-descriptive information

Means, standard deviation and the frequency distribution of the 11 items are provided in Table 4.

Table 4 Frequency and percentage distribution of the 11 PCS items

PCS Items	Value label	Frequency	Percentage
A. Finding out about the disease will help me manage my symptoms.	Neutral Agree slightly Agree strongly	1.0 7.0 12.0	5.0 35.0 60.0
B. Coming to terms with the diagnosis and the disease will make all the difference in coping with my illness.	Neutral Agree slightly Agree strongly	1.0 3.0 16.0	5.0 15.0 80.0
C. Being in control of my illness depends on my individual effort.	Disagree slightly Agree slightly Agree strongly	1.0 4.0 15.0	5.0 20.0 75.0
D. Positive thinking plays an important part in controlling my illness.	Neutral Agree slightly Agree strongly	2.0 2.0 16.0	10.0 10.0 80.0

E. Keeping myself cheerful helps me to control my illness.	Disagree slightly Agree slightly Agree strongly	1.0 4.0 15.0	5.0 20.0 75.0
F. Finding a "happy medium" or "striking a balance" allows for improvement in my coping with the illness.	Disagree slightly Neutral Agree slightly Agree strongly	1.0 3.0 2.0 14.0	5.0 15.0 10.0 70.0
G. The course of my illness can be altered by way of thinking positively.	Disagree strongly Disagree slightly Neutral Agree slightly Agree strongly	1.0 2.0 3.0 5.0 9.0	5.0 10.0 15.0 25.0 45.0
H. Mental strategies such as "mind over matter" help alter the course of my illness.	Disagree strongly Disagree slightly Neutral Agree slightly Agree strongly	3.0 3.0 4.0 3.0 7.0	15.0 15.0 20.0 15.0 35.0
I. I cope with the disease by depending on assistance from other people.	Agree strongly Agree slightly Neutral Disagree slightly Disagree strongly	2.0 6.0 2.0 4.0 6.0	10.0 30.0 10.0 20.0 30.0
J. I have little or no control over my illness.	Agree strongly Agree slightly Neutral Disagree slightly Disagree strongly	2.0 4.0 1.0 8.0 5.0	10.0 20.0 5.0 40.0 25.0
K. Drugs are the only agent that enables me to cope with my exacerbation of symptoms,	Agree strongly Agree slightly Neutral Disagree slightly Disagree strongly	1.0 1.0 1.0 5.0 12.0	5.0 5.0 5.0 25.0 60.0

With the PCS an individual can obtain a total score ranging from plus 16 and minus 16. The median split falls between zero and one; therefore a score of =>one will be considered as Internal perceiver and a score of =<zero External perceiver.

3.4.2 PCS Reliability Analysis

Table 5 Internal consistency of the PCS pre and post intervention

PCS items	Pre	N=20	Post	N=20
	corrected item total correlation	alpha with item removed	corrected item scale correlation	alpha with item removed
A	.2753	.7435	.5131	.8491
B	.5279	.7270	.6958	.8399
C	.5286	.7195	.7196	.8358
D	.4828	.7265	.7452	.8332
E	.4116	.7305	.5869	.8432
F	.4233	.7265	.5525	.8487
G	.4951	.7147	.7563	.8295
H	.4516	.7251	.5849	.8435
I	.2966	.7521	.1892	.8746
J	.3880	.7336	.4308	.8591
K	.4221	.7258	.5425	.8466
CRONBACH'S ALPHA	.7481		.8581	

The internal consistency of the PCS was determined by calculating the item total correlation coefficients before and after intervention as shown in Table 5. As can be seen, the correlations were all in the moderate range suggesting that each

of the items is at least partially measuring the same underlying construct, except for PCS items A, I and J which were lower than the rest of the items (significance levels for a sample size of 20 is 0.561 at $p<0.01$ and 0.444 at $p<0.05$). In addition, all of the items seem to add equivalently to Cronbach's Alpha - i.e., the alpha level remained unchanged when individual items were systematically removed from the scale. Cronbach's alpha for the entire 11 item scale was .75 before intervention and .89 after intervention. This result compares favourably with the alpha value of 0.6 recommended by Nunnally (1978) for scales to be used in basic research.

Overall the PCS seems to exhibit an acceptable level of internal consistency.

3.4.3 PCS inter-item relationship:

The relationship between the items of the PCS was attempted by using the Prinicipal Components Analysis (PCA) and the Varimax Rotation Matrix (VRM). The later was carried out to assess the weightings.

It is unconventional to select the PCA in view of the small sample size.The reason for choosing the PCA for this part of the study was to extract a summary from the data set and reduce the variables down to a smaller number of components. Besides, Tabachnick and Fiddell (1996) stated that "the required sample size also depends on the magnitude of population correlation and the number of factors i.e if there are strong reliable correlations and a few distinct factors a smaller sample size is adequate" (page 640). The statisticlal tables in Tabachnick et al (1996) reported that for a group of 20 subjects, the significance level to adhere to was 0.56 at $p<0.01$ or 0.44 at $p<0.05$. In view of the fact that there were only 20 subjects in this part of the study a more rigid statistical

significance levels was adhered to i.e a significance level of 0.56 at $p<0.01$ rather than 0.44 at $p<0.05$ as recommended by Nunnally (1978).

Tables 5.1 and 5.2 provide the initial statistics of the PCA and VRM of the PCS eleven items.

Table 5.1 Results of the initial PCA of the PCS items

Items	Commonality	Component	Eigen Value	% of Var.	Cum %
PCS A	1	1	3.89139	35.4	35.4
PCS B	1	2	2.25786	20.5	55.9
PCS C	1	3	1.38297	12.6	68.5
PCS D	1	4	1.14227	10.4	78.9
PCS E	1	5	.75606	6.9	85.7
PCS F	1	6	.65703	6.0	91.7
PCS G	1	7	.47531	4.3	96.0
PCS H	1	8	.17700	1.6	97.6
PCS I	1	9	.16654	1.5	99.1
PCS J	1	10	.06534	.6	99.7
PCS K	1	11	.02824	.3	100.0

Table 5.2 VRM of the 11 PCS items

Items	Component1	Component2	Component3	Component4
PCS A	.27471	.39584	- .31695	.47099
PCS B	.49364	.81577	- .05834	.09330
PCS C	.11795	.86085	.31281	.05142
PCS D	.92530	.25529	.04755	.02278
PCS E	.93105	.10361	.12119	- .01976
PCS F	.60843	.59242	- .08049	.06142
PCS G	.16664	.05273	.93515	.06758
PCS H	- .06492	.15846	.88456	.16397
PCS I	- .16637	.10518	.11845	.83202
PCS J	.04303	.43934	.11033	.46845
PCS K	.30380	- .35165	.45274	.67407

From Table 5.2 it can be deduced that PCS items A (Finding out about this disease will help me manage my symptoms) and J (I have little or no control over my illness) have the least component loadings of less then 0.56 (at $p<0.01$). To be retained, an item was required to load at the 0.56 level or more. Items A and J loaded at 0.47 and 0.46 respectively, therefore these two items were removed and a further PCA with varimax rotation was carried out with the remaining items as shown in Tables 5.3 and 5.4.

Table 5.3 PCA of the 9 remaining PCS items

Item	Commonality	Component	Eigen Value	% of Var	Cum %
PCS B	1	1	3.54599	39.4	39.4
PCS C	1	2	2.20113	24.5	63.9
PCS D	1	3	1.20439	13.4	77.2
PCS E	1	4	1.05301	11.7	88.9
PCS F	1	5	.51330	5.7	94.6
PCS G	1	6	.19151	2.1	96.8
PCS H	1	7	.18192	2.0	98.8
PCS I	1	8	.07346	.8	99.6
PCS K	1	9	.03530	.4	100.0

Table 5.4 VRM of the 9 PCS items

Items	Component 1	Component 2	Component 3
PCS B	.43527	- .05385	.85902
PCS C	.05360	.25114	.88231
PCS D	.89877	.06705	.33241
PCS E	.93280	.11652	.15301
PCS F	.54524	- .06123	.67492
PCS G	.15840	.86207	.08275
PCS H	- .06971	.83519	.15455
PCS I	- .28936	.48375	.28333
PCS K	.24718	.76100	- .22526

The above rotated matrix shows that item I (I cope with the disease by depending on assistance from other people) has the least component loading of less than 0.56 (at $p<0.01$). To be retained an item was required to be loaded at the 0.56 level or more. Item I loaded at 0.48 therefore this item was removed and a final PCA with varimax rotation was carried out; the results are shown in tables 5.5 and 5.6.

Table 5.5 The final PCA of the remaining 8 PCS items

Items	Commonality	Component	Eigen Value	% of Var	Cum %
PCS B	1	1	3.53030	44.1	44.1
PCS C	1	2	2.06352	25.8	69.9
PCS D	1	3	1.17779	14.7	84.6
PCS E	1	4	.56143	7.0	91.7
PCS F	1	5	.35984	4.5	96.2
PCS G	1	6	.18591	2.3	98.5
PCS H	1	7	.08585	1.1	99.6
PCS K	1	8	.03535	.4	100.0

Table 5.6 VRM of the 8 PCS items

Items	Component 1	Component 2	Component 3
PCS B	.54840	- .05981	.78192
PCS C	.12246	.28298	.89527
PCS D	.92713	.07277	.23565
PCS E	.91475	.14001	.08246
PCS F	.65317	- .08723	.57189
PCS G	.08448	.92325	.14376
PCS H	- .10901	.87316	.21277
PCS K	.32592	.68426	- .37451

The final rotated component matrix of the 8 PCS items (table 5.6) reveals three components. Component one includes items D, E and F which are "positive thinking plays an important part in controlling my illness", "Keeping myself cheerful helps me to control my illness" and "finding a 'happy medium' or 'striking a balance' allows for improvement in my coping with the illness" respectively. Component 2 comprises of items G, H and K; these items are "the course of illness can be altered by way of thinking positively", "mental strategies such as 'mind over matter' help alter the course of the illness" and "drugs are the only agent that enables me to cope with my exacerbation of symptoms". Component 3 includes items B and C which are "coming to terms with the diagnosis and the disease will make all the difference in coping with my illness" and "being in control of my illness depends on my individual

effort". These three components identify attitude and adjustment to illness and physical and psychological coping. Further research is needed to establish these components into definite factors.

It was decided on the basis of these analyses that the final scale will be revised and the scale will comprise of 8 items. In view of the nature of chronic illnesses, it was also the intention of the author to keep the devised scale short to ensure patient co-operation. As from here the analyses will only include the 8 items. The final version of the scale is attached in appendix (4).

Table 5.7 Correlation of the PCS items

	B	C	D	E	F	G	H	I
B. Coming to terms with the diagnosis and the disease will make all the difference	–	.8025 P=.001	.6553 P=.002	.5457 P=.013	.7344 P=.001	.0581 P=.808	-.000 P=.001	-.0424 P=.859
C. Being in control of my illness depends on my individual effort		–	.3118 P=.181	.2417 P=.305	.4599 P=.041	.3805 P=.098	.3200 P=.169	.0063 P=.979
D. Positive thinking plays an important part in controlling my illness			–	.8494 P=.001	.7380 P=.001	.1752 P=.460	.0747 P=.754	.1988 P=.401
E. Keeping myself cheerful helps me to control my illness				–	.5347 P=.015	.2661 P=.257	.0376 P=.875	.2566 P=.275
F. Finding a 'happy medium' or 'striking a balance' allows for improvement in my coping with the illness					–	.0655 P=.784	.0520 P=.828	-.0839 P=.725
G. The course of illness can be altered by way of thinking positively						–	.7784 P=.001	.5025 P=.024
H. Mental strategies such as 'mind over matter' help alter the course of the illness							–	.3604 P=.118
I. Drugs are the only agent that enables me to cope with my exacerbation of symptoms								–

Correlations among the PCS items are displayed in table 5.7. Perhaps the most notable feature about these correlations is the fact that (with very few exceptions) the items are reasonably intercorrelated at $p<0.05$.

3.5 Construct Validity: Correlation between PCS total scores HAD-A, HAD-D, GHQ & COPE total scores

3.5.1 PCS total scores and HAD-A, HAD-D and GHQ total scores

Table 6 Correlation of PCS total scores with HAD-A & HAD-D & GHQ total scores pre and post intervention

Variable	PCS Totals			
	Pre		Post	
	Correlation Co-efficient	P Value (2 tailed)	Correlation Co-efficient	P Value (2) tailed
HAD-A Total	-.1642	0.489	- .0889	0.709
HAD-D Total	- .3890	0.090	- .1211	0.611
GHQ Total	-.2255	0.339	-.3146	0.177

To determine the validity of the PCS with that of HAD-A, HAD-D and GHQ Scales, the total score of the PCS was computed and correlated with HAD-A total, HAD-D total and the GHQ total scores. The correlation coefficients are shown in Table 6. The scores did not show significant correlation between the scales.

3.5.2 Correlation between PCS total scores and COPE total scores

Table 7 Correlation between PCS Total Scores with that of the COPE total scores pre and post intervention

Cope Variables	PCS			
	Pre		Post	
	Correlation Co-efficient	P - value 2 tailed	Correlation Co-efficient	P - value 2 tailed
Active coping	.2073	.380	- .1480	.534
Planning	.0102	.966	.0158	.947
Seeking instrumental social support	.1809	.445	.0672	.778
Seeking emotional social support	.1478	.534	- .1608	.498
Suppression of competing activities	.2682	.253	.0352	.883
Religion	- .0988	.679	- .0951	.690
Positive reinterpretation and growth	- .0884	.711	- .0749	.754
Restraint coping	.2173	.357	- .0828	.729
Acceptance	.0476	.842	- .2442	.299
Focus on and venting of emotions	- .0177	.941	- .1239	.603
Denial	- .1040	.663	- .1687	.477
Mental disengagement	- .1324	.578	- .1860	.432
Behavioural disengagement	- .2850	.223	.0613	.797
Alcohol/Drug use	- .1635	.491	.1267	.594
Humour	.3490	.131	.0034	.989

Table 7.1 Correlation of PCS Components with GHQ, HAD Scale and COPE Scale (two-tailed)

Variables		**PCS**	
	Component 1	**Component 2**	**Component 3**
GHQT	-.0228 P=.924	-.3274 P=.159	.0311 P=.897
HAD-A	-.1531 P=.519	-.0996 P=.676	-.1118 P=.639
HAD-D	-.3785 P=.100	-.2851 P=.223	-.1083 P=.649
A. Active Coping	.2990 P=.200	-.0019 P=.994	.2984 P=.201
B. Planning	.0498 P=.835	-.0719 P=.763	.1448 P=.543
C. Seeking Instrumental Social Support	.0788 P=.741	.1433 P=.547	.1874 P=.429
D. Seeking Emotional Social Support	.3559 P=.123	-.0300 P=.900	.0457 P=.848
E. Suppressions of Competing Activities	.4001 P=.081	.0064 P=.978	.3400 P=.142
F. Religion	.0152 P=.949	-.1187 P=.618	-.0946 P=.692
G. Positive Reinterpretation and Growth	-.0769 P=.747	-.1162 P=.626	.0955 P=.689
H. Restraint Coping	***.6239*** ***P=.003***	-.1351 P=.570	.1361 P=.567
I. Acceptance	-.0299 P=.901	-.0457 P=.848	.3554 P=.124
K. Denial	-.0558 P=.815	-.1883 P=.427	.1897 P=.423

L. Mental Disengagement	***-.4837*** ***P=.031***	.1217 P=.609	-.0109 P=.964
M. Behavioural Disengagement	.0221 P=.926	***-.5254*** ***P=.017***	.2468 P=.294
N. Alcohol/Drug Use	.0469 P=.844	-.3207 P=.168	.1342 P=.573
O. Humour	.3535 P=.126	.1699 P=.474	.3004 P=.198

The validity of the PCS Total Score was computed and correlated with the COPE Total Scores. The correlation coefficients are shown in Table 7 and there are no significant correlations between the PCS total scores and the COPE Scale. When correlated with the three component structures of the PCS, three subscales of the COPE (restraint coping, mental disengagement and behavioural disengagement) correlated significantly ($p<0.05$) as shown in table 7.1. but this correlation is about what one would expect by chance alone, as there are 51 correlations.

3.6 Analyses - pre and post intervention

To analyse the outcome of intervention the paired t-test was carried out.

3.6.1 PCS Total Scores pre and post intervention

With the PCS an individual's total score can range between plus 16 and minus16. The median split falls at zero and one, it was decided that a score of =>one will be considered as Internal perceiver and a score of =<zero External perceiver.

Table 8 Number of subjects and PCS total Scores pre and post intervention

Variable	Pre		Post	
	Score of =<0	Score of =>1	Score of =<0	Score of =>1
	N	N	N	N
PCS Total	0	20	2	18

Table 8 shows all 20 subjects (100%) to have total scores of one or above indicating that they were internal in their perception. The PCS Total Score before intervention ranged between two and sixteen. Following Conventional Rehabilitation Programme (CRP) the scores of the PCS ranged between minus fourteen and plus sixteen. Two subjects following CRP intervention became external perceivers (scores of =<0). Case studies of these two individuals are presented in the discussion section.

Table 8 (i) shows that 18 subjects remained internal perceivers before and after intervention; two subjects became external perceivers following intervention.

Table 8 (i) A 2x2 table to illustrate the change in the number of subjects before and after intervention.

		Pre-intervention		
		Internal Perceivers	External Perceivers	Total
Post-intervention	Internal Perceivers	18	0	18
	External Perceivers	2	0	2
	Total	20	0	20

The McNemar Test was carried out to ascertain the significance of change; the obtained value of 0.5 is less than the critical value of 3.84 (1df) indicating that the change is not significant at the 5% level.

Table 9 PCS - mean, SD and comparison of means (paired t-test)

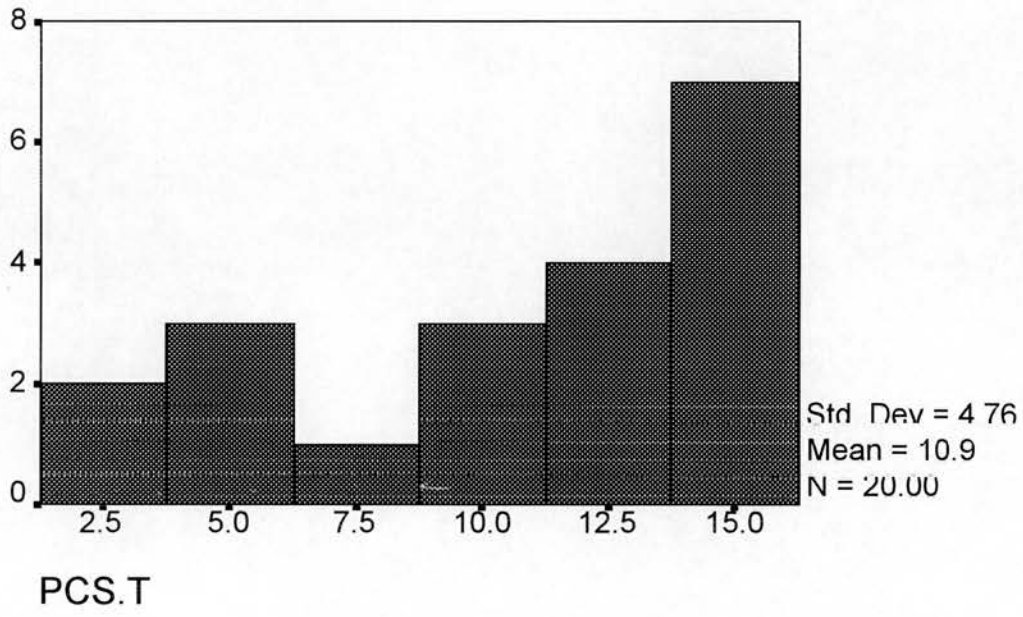
Variable	Before		After		t value	p value (2 tailed)
	mean	SD	mean	SD		
PCS Total	10.85	4.760	8.90	7.35	-1.34	.197

Comparison of means (t -test) was carried out on the PCS total scores before and after intervention and the results were not significant as shown in Table 9.

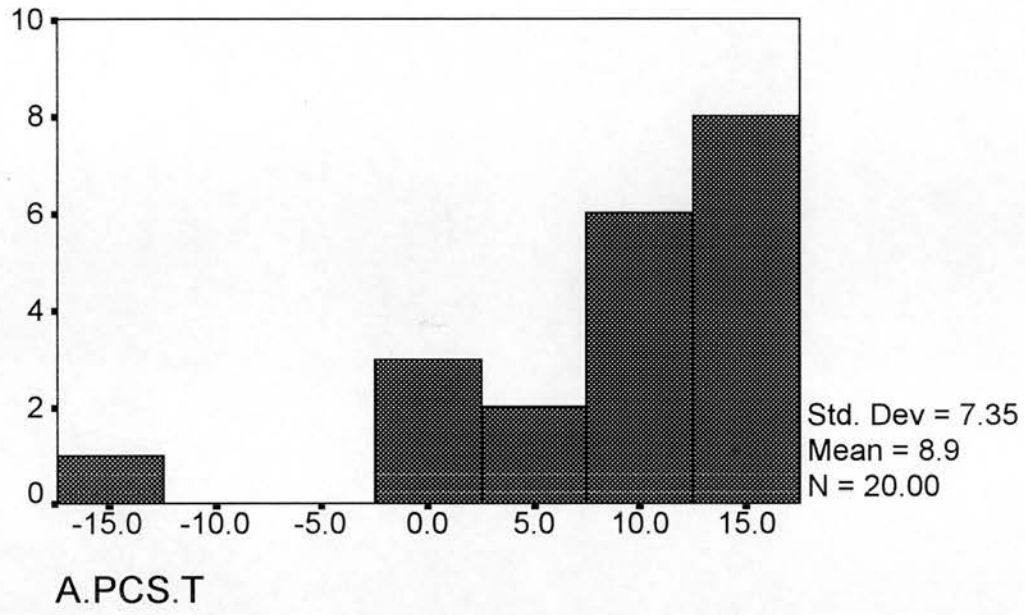
This result is not surprising as all 20 subjects were internal perceivers before intervention and 95% of the subjects were attending the CRP for mobility related problems (70% of the subjects attending for mobility problems alone, a further 15% for problems of mobility and medical problems, 5% for medical problems alone and another 5% for emotional and mobility problems). The CRP is not aimed at addressing perception of coping therefore CRP is not expected to change perception of coping anyway.

There is also a discrepancy in the standard deviation scores before and after intervention; this has arisen as a result of one subject obtaining a score of minus 14 after intervention; as shown in the graph histogram (graphs 1 & 2)

Graph 1: Mean, SD, and number of subjects pre CRP intervention



Graph 2: Mean, S.D. and Number of subjects -PCS total after intervention



3.6.2 HAD-A, HAD-D total scores before and after intervention

The scores before intervention ranged between zero to 14 for HAD-A and one to 8 for HAD-D. The scores after intervention ranged between zero and 14 for HAD-A and zero to 11 for HAD-D.

Table 10 Number of subjects and HAD Scores before and after intervention

Variable	Before		After	
	Score of =<10	Score of =>11	Score of =<10	Score of =>11
	N	N	N	N
HAD A	16	4	18	2
HAD D	20	0	18	2

With the HAD-A and HAD-D a score of 11 and above will indicate caseness and a score of 10 and below non caseness.

Four subjects obtained scores of => 11 before intervention for HAD-A and following intervention this was reduced to two subjects, i.e., obtaining scores of => 11. However, the number was reversed for HAD-D; none had a score of =>11 before intervention but 2 subjects obtained scores of => 11 following intervention (Table 10).

Tables 10 (i) and 10 (ii) show the caseness and non caseness before and after intervention for anxiety and depression. The McNemar Test was carried out to ascertain the significance of change. For anxiety the observed value of Chi-square was 0.25, and the critical value of Chi-square for one degree of freedom ($p< 0.05$ two tailed) is 3.84, suggesting that there is no difference between the anxiety caseness and non caseness pre and post intervention.

For depression the observed value of Chi-square, incorporating the correction for continuity was 0 highlighting no significant difference between the caseness and non-caseness pre and post intervention at $p<0.05$ (two tailed).

Table 10 (i) 2 x 2 table - caseness and non caseness for anxiety pre and post-intervention

		Pre-intervention		
		Caseness	Non caseness	Total
Post-intervention	Caseness	1	1	2
	Non caseness	3	15	18
	Total	4	16	20

Table 10 (ii) 2 x 2 table caseness and non caseness for depression before and after intervention

		Pre-intervention		
		Caseness	Non caseness	Total
Post-intervention	Caseness	0	1	1
	Non caseness	0	19	19
	Total	0	20	20

The means and SD of scores for the 20 subjects before and after intervention are presented in Table 11 along with the comparison of means.

In HAD-D there is a slight increase in the mean score after intervention although this increase is not statistically significant, as shown by the t - test. The standard deviation for the HAD-D is also higher after intervention and this is due to the one patient obtaining an extreme score of 14.

Table 11 HAD Scale - mean, SD and comparison of means (paired t test - 2 tailed)

Variable	Before		After		t value	p value (2 tailed)
	mean	SD	mean	SD		
HAD A	4.90	4.67	4.75	3.82	.20	.84
HAD D	4.45	2.61	4.50	3.43	.10	.94

3.6.3 Analysis of GHQ - pre and post intervention

The GHQ scores before intervention ranged between zero and four for GHQ-A; zero to five for GHQ-B; zero to six for GHQ-C; zero to seven for GHQ-D and zero to 20 for GHQ-T. Following intervention the scores ranged between zero and five for GHQ-A; zero and six for GHQ-B; zero and three for GHQ-C; zero and five for GHQ-D and zero and 14 for GHQ-T.

Table 12 Number of subjects and GHQ Scores before and after conventional rehabilitation programme.

Variable	Before		After	
	Scores of =<5 N	Scores of =>6 N	Scores of =<5 N	Scores of =>6 N
GHQ-A	20	0	19	1
GHQ-B	18	2	17	3
GHQ-C	19	1	20	0
GHQ-D	18	2	19	1
GHQ-T	13	7	13	7

Scores of =>6 are indicative of psychiatric caseness, Table 12 shows scores of psychiatric caseness and non-caseness before and after CRP. There is no change before and after intervention in the number of subjects achieving scores of =>6 following intervention in GHQ-A, with one person showing an increase in GHQ-B. In GHQ-C and D there is a decrease in the number of psychiatric caseness post intervention. The GHQ-T shows no change in caseness following intervention.

The McNemar Test showed no significant change between pre and post intervention between caseness and non caseness at $p<0.05$ level two tailed (observed value of Chi-square was 0; critical value is 3.84) as shown in table 12.1..

Table 12.1 2 x 2 table: Psychiatric caseness and non caseness before and after intervention

		Pre-intervention		
		Caseness	Non caseness	Total
Post-intervention	Caseness	4	2	6
	Non caseness	3	11	14
	Total	7	13	20

Table 13 GHQ - mean scores, SD and comparison of means (paired t-test)

	Before		After		t	p
VARIABLE	mean	SD	mean	SD	value	value
GHQ-A	1.55	1.70	1.50	1.50	0.12	. 91
GHQ-B	1.75	1.68	1.30	2.00	1.03	.32
GHQ-C	0.90	1.55	0.75	0.85	0.51	.61
GHQ-D	1.05	2.09	0.45	1.19	2.04	.05
GHQ-T	5.25	5.50	4.00	4.12	1.22	.24

The comparison of means (paired t-test) does not show a significant change in the caseness scores following intervention except in GHQ-D (GHQ-D - before: mean = 1.05, SD = 2.09; after: mean = 0.45, SD = 1.19; $t = 2.04$, $p<0.05$ one tailed) as shown in Table 13.

3.6.4 Analysis of COPE Scale before and after intervention

Table 14 Number of subjects and COPE Scores before and after intervention

	Variable	Before		After	
	COPE - Scales	Score of 4 - 8 (N)	Score of 9 - 16 (N)	Score of 4 - 8 (N)	Score of 9 - 16 (N)
A	Active Coping	8	12	6	14
B	Planning	3	17	6	14
C	Seeking instrumental social support	8	12	6	14
D	Seeking Emotional social support	7	13	10	10
E	Suppression of competing activities	8	12	12	8
F	Religion	6	14	9	11
G	Positive reinterpretation and growth	15	5	14	6
H	Restraint coping	1	19	3	17
I	Acceptance	8	12	9	11
J	Focus on and venting of emotions	12	8	9	11
K	Denial	16	4	16	4
L	Mental disengagement	17	3	15	5
M	Behavioural disengagement	5	15	6	14
N	Alcohol/Drug use	19	1	19	1
O	Humour	5	15	7	13

With the COPE scale a score of 4-8 is considered positive in the following subscales: (E) suppression of competing activities, (F) religion, (K) denial, (M) behavioural disengagement, and (N) alcohol/drug use. Two subscales of the COPE i.e (J) focus on and venting of emotions and (O) humour, scores of 9-6 is interpreted as either being a positive or a negative score. In the remaining 8

subscales a score of 9-16 is interpreted as positive and a score of 4-8 is interpreted as negative.

Table 14 shows that there has been an increase in the number of subjects engaging in the following coping styles and strategies after intervention: active coping (10%), seeking instrumental social support (10%), positive reinterpretation and growth (5%), restraint coping (10%), focus on and venting of emotions (15%), and mental disengagement (10%). In the remaining coping styles and strategies there has been either no change or a reduction in the number of subjects using such strategies following intervention. The scores, however, show just two significant changes before and after intervention, suppression of competing activities ($t = 3.41$; $p = 0.01$) and restraint coping ($t = 2.48$; $p = 0.02$) as shown in Table 15. There is a decline in the values of results in the COPE Scale after intervention but in some cases such as denial and alcohol and drug use, a decline is not necessarily a negative indicator.

Table 15 Mean scores, SD and comparison of means (paired t-test)

	Variable	Before		After		t	p Value
	COPE-Scale	Mean	SD	Mean	SD	Value	2 tailed
A	Active coping	10.80	3.38	10.60	3.42	.43	.68
B	Planning	11.30	3.13	10.65	3.48	1.05	.31
C	Seeking instrumental social support	9.75	3.19	10.05	3.85	.46	.65
D	Seeking emotional social support	9.35	3.00	8.65	3.01	1.18	.25
E	Suppression of competing activities	9.75	3.14	8.05	3.63	3.41	.01
F	Religion	9.45	2.98	8.90	2.47	.79	.44

G	Positive reinterpretation and growth	7.35	4.12	7.05	4.59	.49	.63
H	Restraint coping	14.30	2.39	12.40	3.73	2.48	.02
I	Acceptance	9.35	3.03	9.05	3.10	.45	.66
J	Focus on and venting of emotions	9.40	3.87	9.15	3.39	.32	.75
K	Denial	6.55	2.16	5.90	2.94	.99	.33
L	Mental disengagement	5.95	2.35	6.75	2.71	1.39	.18
M	Behavioural disengagement	9.95	3.19	9.75	3.08	.42	.68
N	Alcohol/Drug use	4.95	2.04	4.60	1.82	.63	.54
O	Humour	10.70	3.61	10.65	4.85	.07	.95

3.7 Conclusion

The results of the second part of the study show very clearly that the PCS is a reliable scale but the study has not established validity with the other scales used. In failing to validate with the other scales used in this study, it can be stated that the PCS is not intending to measure the extent of anxiety, depression, psychiatric caseness, or the coping abilities. Therefore, it is acceptable to state that this scale measures a unique concept which is perception of coping. This part of the study has also established that Conventional Rehabilitation Programme has helped individuals eleviate anxiety but not `improve' perception of coping nor depression.

3.8 Summary and Conclusion

The analysis of data from the second part of the study provided interesting results.

The Perception of Control Scale (PCS) initially consisted of eleven items. Using the reliability and principle component statistical methods significant components were extracted and the scale revised. The final version of the scale consisted of 8 items. The 8 items formed three components, which identified perceptions relating to attitudes and adjustment to illness and physical and psychological coping components.

The correlation coefficients between the PCS total scores and the other scales in the study (HAD-A; HAD-D; GHQ and COPE scales) did not highlight a strong significant relationship between them. This to an extent indicates that the PCS is a scale in its own right, measuring a unique component, i.e. the perception of coping.

The results also highlighted that following conventional rehabilitation programmes two subjects became external perceivers from having been internal perceivers. However, a significant change was noted in the depression scale.

In conclusion it can be stated that the PCS is a reliable scale but further analyses on the scale are necessary in order to establish validity using larger sample sizes and other relevant measurement tools.

4. DISCUSSIONS

4.1 Introduction

This study is divided into two parts. The results of these two parts will be discussed with reference to previous research. Methodological weaknesses of the present study and the future clinical and research implications of the results will also be discussed. In addition two case studies will be presented, which will highlight the psychological interventions in improving perception of coping.

4.2 Part One - Development of the Scale

The aim of this part of the study was to develop a measure of perception of coping for use with adult sufferers of chronic progressive illnesses. This was seen to be necessary in order that rehabilitation programmes take into consideration the importance of the perception of the individual in enabling them to cope with the difficult situation they are in. Research evidence to date has shown that generally internal perceivers are better copers than external perceivers (Wallston & Wallston, 1976a and 1976b) because they take more responsibility for their actions (Rotter 1972). If this can be identified with the use of an appropriate measure, then an appropriate rehabilitation programme could be devised and geared to individual need.

4.2.1 Subject Selection

It was found that out of 40 subjects contacted, 36 subjects were agreeable to take part in the study. The reasons for the four subjects not wanting to take part in the study were not pursued. This was an oversight as this may have provided some important information about these individuals' emotional reactions, reasons and other relevant information pertinent to Multiple Sclerosis (MS). The 36 subjects who agreed to take part in the study were a highly motivated group of people who were looking for any appropriate coping approach to enable them to have an improved quality of life. They stated that if developing the new scale was going to do that then they were willing to take part in the study. Their motivation and keenness were further highlighted during the interview sessions both with the 16 trial pilot subjects and the 20 experimental subjects. They elaborated their explanations at great length to enable the interviewers to understand their uncertain situation. All subjects were hopeful that a cure will be found in the near future. Hope is an important component in coping with a chronic disabling disease such as MS. Elizabeth Kubler-Ross (1969) for example noted in her book "Death and Dying" while observing patients with chronic and terminal illnesses, "we were always impressed that even the most accepting, the most realistic patients left the possibility open for some cure or the discovery of a new drug or the last minute success in a research project". Some subjects in this part of the study were placing their hopes on the new drug Interferon which is currently being marketed in North America, and were hopeful that they should be considered for this treatment. At present, the available treatment approaches can only offer symptomatic relief; drugs can be used to alleviate inflammation, that is an attempt to down-regulate the immune system in order to reduce the demyelinating process

(Troiano, Cook and Dowling, 1987), and to treat pain, depression, incontinence and spasticity.

4.2.2 Procedure

This part of the study adopted a qualitative research approach which sought to discover the whole complexity of events occurring in the individual's real life. This type of research was seen to be more appropriate for this type of study and for this group of subjects, for the reason mentioned above but this was a time-consuming procedure. Three senior professionals were involved in interviewing the 36 subjects. The pilot interview sessions were found to be more cumbersome due to the three professionals coming from three different disciplines and having to follow a common interviewing format. In addition, finding time for the three individuals to meet was a difficult task. However, this was overcome, and the problems were ironed out before the actual study was undertaken.

The interview sessions were lengthy because the subjects were keen to talk about themselves and their illness, in the hope that advice or any relevant information about their condition would be made available to them. This was seen as therapeutic (Minden, 1992; Day et al, 1953) by the interviewers. It is also worth noting here that the subjects for this part of the study were contacted from the Register kept at the Douglas Grant Rehabilitation Unit in Ayrshire Central Hospital, Ayrshire and these individuals were not in touch with the Rehabilitation Unit during the time of the data collection. Hitherto, when the opportunity arose for them to meet with the professionals for the purpose of this study they took the opportunity to talk at length with them about their situation and condition.

Tape-recordings of the interviews were found to be a very useful procedure for this part of the study as the three interviewers were from different disciplines and the recording helped to extract the appropriate responses. Strauss (1987) argued that tape-recordings are unnecessary because they usually contain much repetition and redundancy. Although this was found to be the case in the current research, this procedure was adopted for the reason given above as well as the fact that this type of research is new to the researcher. The tape-recorded information was then transcribed. The process of producing the complete transcripts, however, was once again found to be time-consuming, although it was found to be useful. From the transcripts the descriptive words and phrases were extracted.

The ten judges who were involved in placing the descriptive words, phrases and statements were volunteers from different professional groups. They all had knowledge of rehabilitation, the processes of rehabilitation, and the concept of locus of control. Despite this, and having been provided with the definition of the three concepts, i.e., internal, external, and neutral, two judges had (judges numbers two and seven) problems completing the statements. When questioned about this, they stated that they had difficulty deciding where the concept fitted in relation to the statements and phrases. Where there was doubt, the judges left these statements blank. The researcher did not pursue completion of the forms in order to avoid bias. These types of difficulties are common in qualitative research, Folkman (1982) for example, cites similar reasons in the research areas of coping. In view of the judges' indecisiveness, where there existed 100% agreement, these statements and phrases were chosen for the development of the PCS.

The completed PCS was tested for readability. The main reason for using the readability tests is to ensure that the scale is readable and understandable by the average population. The average reading age in the UK is estimated to be 9 to 10 years by the organisation, Patient Education Scotland. The readability test carried out highlighted that the PCS was a readable scale. Patient Education Scotland intimated that a text which is easy to read on its own is insufficient. They suggested that it should be easily understood. However, they continued to explain that the argument is only applicable in designing educational material for children, this statement is not intended for assessing health-related materials for adults. The PCS scale was found to be easily understood by the subjects who took part in the second part of the study. The first part of the study successfully resulted in the production of the eleven item scale - the Perception of Coping Scale (PCS).

4.3 Part Two -reliability and validity of the PCS

4.3.1 Introduction

The second part of the study was designed to establish the reliability and validity of the PCS and ascertain if it is also sensitive to change such as intervention.

It has been demonstrated that the PCS is an independent scale and it was not intended to measure levels of anxiety, depression, or psychiatric caseness.

4.3.2 Sample Characteristics

Twenty subjects were recruited for the second part of the study. All the subjects were referred either by their General Practitioners and/or other medical and surgical consultants to the unit. The first contact these subjects had was with the physician at the rehabilitation unit, who explained the research. It was found that all the twenty subjects who saw him agreed to take part in the study highlighting that the physician has been presenting the research in positive terms. This was also evident in the comments made by the subjects. Simes, Tattershall, Coates, Raghavan Solomon and Smart (1986) stated that if a research investigation is described in optimistic terms then patients were more likely to opt to participate in research projects.

There was no drop-out nor missing data in this study, indicating that the subjects' motivation and attitude were positive. 50% of the subjects stated that they were wanting the best care possible, and believed that participation in the study would do that. The research side has also been an influencing factor in that the subjects were attending the rehabilitation unit regularly for rehabilitation purposes. The outcome may have been different if it was in a tertiary care centre or a hospital environment (Nelson, Franklin, Hammam, Boteler, Baum & Burkes, 1988). Nelson et al found that the tertiary care centre patients were younger, had a more active and progressive disease for their age, were more likely to be female, and relied on medical professionals and therapists for their routine care. Thus, this would be unlikely to represent a community population.

4.3.3 PCS Reliability Analysis

The reliability analysis of this scale exhibited that the level of internal consistency was relatively stable, that is, suggesting that each of the items is partially measuring the same underlying construct except for three items. The pre and post analysis can also be viewed as the test re-test analysis as the re-testing was carried out soon after the conventional rehabilitation programmes were completed. The internal consistency post-intervention was highly significant, emphasising that the PCS is a reliable scale. In view of the observed three weak items the principle component analysis was carried out and the three items were discarded. Three components emerged from the principle component analysis. Component one consisted of three items, component two three items and component three two items. These items addressed perception of adjustment and attitude to illness and perception to physical and psychological coping with illness.

With the PCS inter-item correlation, ten significant correlations were identified out of twenty eight correlations. Although the correlations were not very strong the items tended to correlate in conceptually meaningful ways, ie item B, "Coming to terms with the diagnosis and the disease will make all the difference" correlated significantly with items C, D, E and F which are: item C, "Being in control of my illness depends on my individual effort"; item D, "Positive thinking plays an important part in controlling my illness"; item E, "Keeping myself cheerful helps me to control my illness"; and item F, "Finding a 'happy medium' or 'striking a balance' allows for improvement in my coping with the illness".

Item G, "The course of the illness can be altered by way of thinking positively" correlated significantly with Items H and K; item H being "mental stragtegies such as 'mind over matter' help alter the course of the illness" and item K, "Drugs are the only agent that enables me to cope with my exacerbation of symptoms".

All these correlations complemented positively with each other, that is showing a relationship.

4.3.4 Construct validity: PCS and other correlations

It was found that the PCS did not correlate significantly with the HAD scales or the GHQ. The PCS total scores did not correlate with any of the COPE subscales. The three components of the PCS individually correlated with three of the COPE subscales but this is about what one would expect to happen by chance alone as there were 51 correlations.

The HAD scale specifically measures psychological symptoms of the more emotional nature, rather than physical symptoms which are often consequences of the emotional state. The GHQ is aimed at detecting psychiatric disorders, while the COPE scale assesses the different ways in which people respond to stress. The current findings demonstrate that PCS did not correlate with any of these measures. The PCS measures another concept, i.e., perception of coping. It is only expected that when the perception of coping becomes external, then the individual's dependency on others increase with regard to coping, resulting in depression becoming an important component (Dinardo, 1972) affecting

perception of coping. With this group of subjects there are significantly more internal perceivers than external perceivers therefore this aspect was not obvious.

MS is a progressive neurological disease where the disease is characterised by variability and uncertainty; attempting to control their health in such circumstances is likely to result in failure and consequently a sense of helplessness and hopelessness develops, which are the classic characteristics of depression (Wortman and Brehm, 1975). It is expected that the individual's perception during this period will be altered as a result.

From these results it can be concluded that the PCS is an independent scale that is not attempting to measure the levels of anxiety experienced by MS patients, not the psychiatric status of the subjects nor the coping style of the MS individuals; instead it measures the perception of coping.

No correlations were noted between the anxiety scores and the PCS scores post-intervention. This highlights that intervention has allowed the individuals to adjust to the disability which no longer consumed all of the individual's energy and freeing energy for other activities. This is a similar view reported by Viney (1986) and Matson and Brooks (1977). In conclusion the PCS has acceptable reliability but validity was not proven. Once validity is established with the use of other appropriate measurement tools, it is hoped that the PCS will be of use to healthcare professionals, who work with chronically ill patients, to identify the perception of coping, in order to plan their rehabilitation. The clinical implications of this scale will be discussed later.

4.4 Intervention Outcome

4.4.1 Levels of psychological morbidity and psychiatric caseness

Levels of anxiety and depression found in the present study were low. Most patients could only be identified as being either mildly anxious or depressed. 20% of the subjects were found to be exhibiting anxiety symptoms. None exhibited any evidence of depression. Over the years studies on Multiple Sclerosis have found high levels of anxiety (Philippopoulos et al, 1958; Caplan and Nadelson, 1980; Burnfield and Burnfield, 1982) and depression (Whitlock and Siskind, 1980 and Young, Saunders and Ponsford, 1976). The present findings on depression and anxiety are therefore contrary to these. However, the evidence for psychiatric caseness as assessed by the General Health Questionnaire highlighted that 35% of the subjects to exhibit psychiatric caseness before intervention. This is one-third of the subject sample. This finding is in line with Surridge (1969) and Rabins and Brooks' (1981) findings. None of these subjects were found to be on any psychotropic drugs such as antidepressants. However, the levels of psychiatric caseness found in the present study could also be due in part to the measurements used. Using a standardised numeric assessment such as the GHQ to measure levels of psychiatric caseness in a population with a neurological chronic disease is difficult, since many of the somatic symptoms of psychiatric origin, anxiety/depression and social dysfunction are similar to those of the disease. For example, sufferers of Multiple Sclerosis often experience as part of their illness, chronic and marked fatigue, and problems in concentration and memory; these are some of the major symptoms of MS which affect their social well-being. Patients often say that they could manage the problems and

symptoms that MS brings if only they were just not so fatigued and had more energy (Murray, 1995).

The current research also used the Hospital Anxiety and Depression Scale which is a more appropriate scale for this population in assessing the levels of anxiety and depression, as this excludes the 'somatic' questions. The studies carried out by Rabbins et al (1981) and Dalos et al (1983) used the General Health Questionnaire to assess the emotional disturbance such as anxiety and depression in their MS subjects. It is also worthwhile mentioning here that the Hospital Anxiety and Depression Scale was only published in 1983, therefore was not in circulation for use in research by the above authors. The levels of anxiety and depression experienced by this group of subjects were low and required no psychological input, except for two individuals, which will be discussed separately in a single case design format.

It was found that 85% of subjects were attending the Unit for mainly mobility related problems, and the remaining 15% of the subjects were attending due to the exacerbation of their MS symptoms. The 85% of subjects were in the remitting stages of their illness and they reported no other physical exacerbation of their symptoms. Being in the remitting stage can be a source of emotional support for the individual as this helps to protect the individual against depression and anxiety. A study by McIvor, Ricklan and Reznikoff (1984) found that patients with the remitting form of the disease are significantly less depressed than those with the progressive, non-remitting form.

Remission seems to be a more acceptable explanation of the results obtained in the present study as patients with the progressive form of Multiple Sclerosis are reported to exhibit high levels of psychological morbidity (Schiffer et al, 1983).

Several studies suggest that levels of depression and anxiety are neurological symptoms of the MS disease itself (Surridge, 1969; Young et al 1976) and will therefore not be affected by methods of coping, length of severity of illness, etc. However, the main levels of anxiety and depression found in this population suggest that if the above is true, it can only refer to those with the progressive form of the disease. Larcombe and Wilson's (1984) study showed that levels of depression in Multiple Sclerosis could actually be reduced by the use of cognitive behavioural therapy techniques. This suggests that psychological morbidity can be a symptom of the disease, resulting from the thoughts and attitudes the patients have and the ways they react to their disability. However, it is difficult to conclude from the treatment approaches the etiology of the disease.

4.4.2 COPE Scale

The COPE results showed that the subjects of this study were engaged in various forms of coping methods in order to relieve their stress. These results are similar to those reported by the collaborative study of Hamburg and Adams (1967).

The COPE results highlighted that 70% of the subjects were involved in active coping. This involves subjects taking their own initiative to take action and exerting their own efforts in trying to remove or circumvent their stresses. 85% of the subjects were involved in thinking about how to cope with their stressor,

that is, how to confront the stressor and coming up with the action strategies to best handle the problem, accordingly 60% of the subjects were found to seek assistance, information or advice about what to do about their situation. 65% of the subjects sought sympathy or emotional support from someone in dealing with their situation. This type of coping would seem to be functional in many ways, that is, the person who is made insecure by a stressful transaction can be reassured by obtaining this sort of support. On the other hand, sources of sympathy sometimes are used more as outlets for the ventilation of one's feelings. 60% of the subjects were found to suppress their attention on other activities that they may engage in, and instead they concentrated solely on dealing with the problem at hand. 70% of the subjects were found to be engaged in religious activities as a coping response. Data collected by McCrae and Costa (1986) suggests that such a coping tactic may be quite important to many people. One might turn to religion as a source of emotional support or as a tactic of active coping with a stressor. Kubler-Ross, for example, (1969), reported that faith and hope give the patients' plight some mission and meaning to handle their situation. Only 25% of the subjects felt that they could use their situation to grow from it or even to view their situation in a favourable light. The value of this tendency is that, it allows the individual to continue to cope actively with the emotional distress. In view of the fact that Multiple Sclerosis is a progressive disease, with a variety of neurological symptoms, following an unpredictable course, this type of response is acceptable. Coping passively by holding back one's coping attempts was not found to be the case with this group of subjects; 95% of these subjects were found to engage in unrestrained coping, that is, not waiting until an appropriate opportunity presented itself. Instead they were using any tactic to cope with the stressor. 40% of the subjects reported that they did not wish to accept the fact that the stressful situation has occurred and that it is for real. Being able to accept that a stressful event has

occurred enables individuals to look at a way of coping. This aspect also raises the question of what do we do typically in the face of painful elements of experience. Literature in the area of psychiatry and psychology provide the impression that one avoids the painful elements at all costs, even if this requires extensive self-deception. Examples of this type of coping are denial, repression, isolation, etc. These mechanisms rely heavily upon avoidance and such mechanisms only represent one important class of response to threatening elements. 60% of the subjects were found to be suppressing their emotional distress, in order to concentrate more fully on the challenges or threat at hand, although being aware of the emotional distress. Denial was used by only 20% of the subjects and mental disengagement, such as daydreaming or sleep, by 15% of the subjects. Denial is a controversial response. It is often suggested (Cohen & Lazarus, 1973) that denial is useful for minimising distress and thereby facilitating coping. Alternatively, it can be argued that denial only creates additional problems unless the stressor can profitably be ignored. That is, denying the reality of the event allows the event to become more serious, thereby making more difficult the coping that eventually must occur (Matthew et al, 1983). Mental disengagement functions as an anxiety "reliever" as this enables one to take one's mind off a problem. These types of tactics are more diverse than the other coping categories so far discussed. 75% of the subjects reported that they physically disengaged themselves from the goal with which the stressor is interfering such as waiting for the right time to do a certain task or holding off doing anything until the situation permits. These types of coping strategies are termed as restrained coping strategies. It sometimes is a necessary and functional response to stress. 75% of the subjects also reported that they use sense of humour about the stressor which lightens their distress. Alcohol and recreational drugs did not play a major role in coping with their stressor, except for one person.

For the individuals in this study, reality is disrupted by the occurrence of a chronic disease, the emerging reality for these individuals is learning to cope with the stress associated with the disease and to live with the problem. In general the subjects in this study used both problem-focused and emotion-focused strategies, but the three strategies most frequently used were with in the problem-focused coping, i.e., trying to maintain some control over the situation, trying out different methods of problem-solving, and looking at the problem objectively to see all sides. These approaches did not alter greatly post intervention.

4.4.3 Perceived Control Scale

In this study no subjects exhibited external coping perception pre intervention but 10% exhibited external coping perception post intervention. For these subjects the perception of their disease and coping were outside their control. Parkes (1984) suggested that this dimension may influence the appraisal of these patients' personal potential to alter the stressor. Researchers such as Butterfield (1964), MacDonald and Games (1972), and Kilpatrick, Dubin and Marote, (1974) have shown a belief in external locus of control to be related to debilitating anxiety to the holding of irrational values to mood disturbances and to indices of maladjustment. The current finding is correlative and there is no way of knowing if external perception accompanies predisposition to psychological difficulties or if these perceptions occur as a function of the disturbance. 100% of the subjects pre intervention and 90% post intervention were internal perceivers. On the basis of these findings, the coping patterns discussed in the previous section are much clearer, i.e., a great majority of the subjects in this study were taking some personal control to cope with their

situation. This suggests that rehabilitation goals and intervention strategies address the person's appraisal of disability. This can give rise to two different issues, i.e., rehabilitation not producing the desired outcome in subjects or the individuals giving in to their disability or even negatively appraising the rehabilitation potential and the associated disabilities. It is also possible that once there is improvement in psychological symptoms subjects are less motivated to engage in active problem solving.

It was found that 85% of the subjects that took part in the study presented with problems of mobility. It was only appropriate that they receive the conventional rehabilitation programmes, which involved physiotherapy and medical intervention where appropriate. These programmes did not retain the number of internal copers. In fact, following post-intervention the number of internal perceivers reduced by 10%. Medical intervention and physiotherapy interventions on their own are insufficient to alter the perception of coping in this group of subjects. Physical therapy can only increase mobility and prevent disuse atrophy of the muscles and medical therapy, particularly drug therapy, to alleviate inflammations. In this circumstance, rehabilitation was directed at managing and altering the source of stress that is the problem for the 85% of the subjects and not the emotion or the perceptions associated with the problem. The nature of physiotherapy is to keep patients active, but the nature of the MS disease is fatigue and tiredness, which can only hightlight the individual's disabilities further, and their failure to achieve their set goal or outcome, further affecting the individual's perception of coping. It has been stated by Folkman (1982) that problem and emotion-focused coping are each capable of facilitating the other. Although this was found to be the case to a lesser extent, these factors were non-significant except in GHQ-D. These results have implications for the future management of patients with MS. It is perhaps important to foster

patients' beliefs in their own control in contrast to someone else solving the problems as the emphasis is on external control: for instance, the physiotherapist and the doctor being in control of the patient to get the patient better. It would be useful to develop a programme to change patients' perceptions towards greater internality in order to help the disabled individual to achieve more control over the situation. Kaplan, Aitkins and Reinsch (1984) found that various behavioural interventions increased the belief in control and adherence to exercise programmes for patients with chronic obstructive pulmonary disease, therefore integrating psychological approaches can only improve the situation as will be demonstrated by the two case studies to be presented in the next section. Subject numbers 10 and 19 were chosen for this purpose as subject 10 obtained a PCS total score of zero after CRP intervention (pre intervention score was five). Subject number 19 obtained a PCS total score of minus 14 post CRP intervention (pre intervention score being ten). The combination of modified Stress Innoculation Programme (Mischenbaum, 1977) and (Schwartz and Rogers' 1994) Coping Flexibility Intervention Approach were used with these two individual cases.

4.4.4 Psychological Treatment Approach

The treatment package consisted of a semi-structured training programme. The training operations were flexible, which were adapted to the MS patient. The training combined elements of instructive teaching, philosophical discussions, cognitive restructuring, problem-solving, relaxation training, behavioural and imaginal rehearsal, self-monitoring, self-instruction, and self-reinforcement and efforts at changing the environment. The aim of this was to nurture the individual and help the individual develop coping skills to resolve immediate problems and to apply these approaches in the future, to solve difficulties. It

provides a proactive defence or skill to deal with current and future stressful situations.

A six session procedure was integrated in the psychological intervention. The two subjects were seen on an individual basis. Each session lasted between 45 minutes and to one hour, and each subject was seen over a period of three months, on a fortnightly basis.

These sessions adopted the following format:

Session One included training on the understanding of the nature of stress, training in self-monitoring of daily stresses and the consequences of this on behaviour, cognition, emotion, and the physiological aspects.

Session Two concentrated on enhancing self-monitoring, giving feedback on this, and constructing muscle relaxation exercises, where necessary organising a relaxation tape for the individuals.

Session Three involved discussions from previous sessions and examining cognitive responses to daily stressors.

Session Four involved teaching to identify stress cues, helping individuals restructure cues and identify negative interpretations.

Sections Five and Six focused on role-playing as to how to cope with a potentially distressing situation while integrating the self-monitoring, self-cueing cognitive restructuring and physiological coping skills.

Session Seven was spent reviewing the programme and completing the assessment tools.

4.4.4. (i.a) Case Study One

Mrs G was a 41 year old married woman, who had developed symptoms of MS four years before she was diagnosed in June of 1995. During the four years she said that she had been consulting a Neurologist, but the diagnosis of MS was withheld until she started falling about and her ability to do physical tasks deteriorated. Following diagnosis, the Neurologist withdrew her support. Mrs G reported feeling abandoned, without any support or preparation. Throughout the four years of waiting for her diagnosis, she stated that she suspected MS, but did not wish to acknowledge this. On one occasion she said that she contacted the MS organisation but she was refused help as she had not been diagnosed with the disease. Despite the suspicions, when the diagnosis was made, she reported feeling devastated by the diagnosis. She was initially referred to the Douglas Grant Rehabilitation Unit, Ayrshire Central Hospital, Ayrshire, by her General Practitioner in early July of 1995, regarding her mobility problems. At that stage, the MS Questionnaires were completed and that formed the initial assessment on 18th July 1995. She continued to attend for physiotherapy input. Physiotherapy input was completed by early January of 1996 and the second MS assessments tools were completed. Her scores indicated a major improvement in her mobility and reduced falling, compared to the initial assessment. She also reported no longer having to use a wheelchair and being able to walk with the help of a walking aid. Her PCS score was however, external from having been internal before intervention. She began to talk about her anger and frustration surrounding her diagnosis and the various domestic problems. She reported that she is a mother of two teenage children,

who themselves were experiencing problems adjusting to her disability and the disease. Although she has a very supportive husband, her two children's reactions, she said, were difficult for her cope with. Up until about June of 1994 she worked as a full-time Civil Servant, but had given up her work due to the deterioration of her condition.

Mrs G was seen over a period of 7 sessions for psychological intervention. The procedure was as mentioned above. The seven sessions addressed the problems associated with the diagnosis, losses that arose from this illness, and disability and the different ways that people cope with them. The negative feelings of anger, resentment and fear were also addressed. A session was spent improving communication between her and her children. Effective problem-solving and goal-setting tasks were also included, to promote the sense of control and reduce the perception of failure. Stress management and relaxation techniques were discussed and explained. Homework assignments were given at the end of each session, and during the start of each session these assignments were reviewed. The results of the psychological intervention, along with the previous assessments, are detailed below in a graphical format.

4.4.4 (i.b) Result

4.4.4 (i.b.i) The COPE Scores

Table 16 Mrs G's COPE scores: before intervention, following physiotherapy intervention and finally psychological intervention

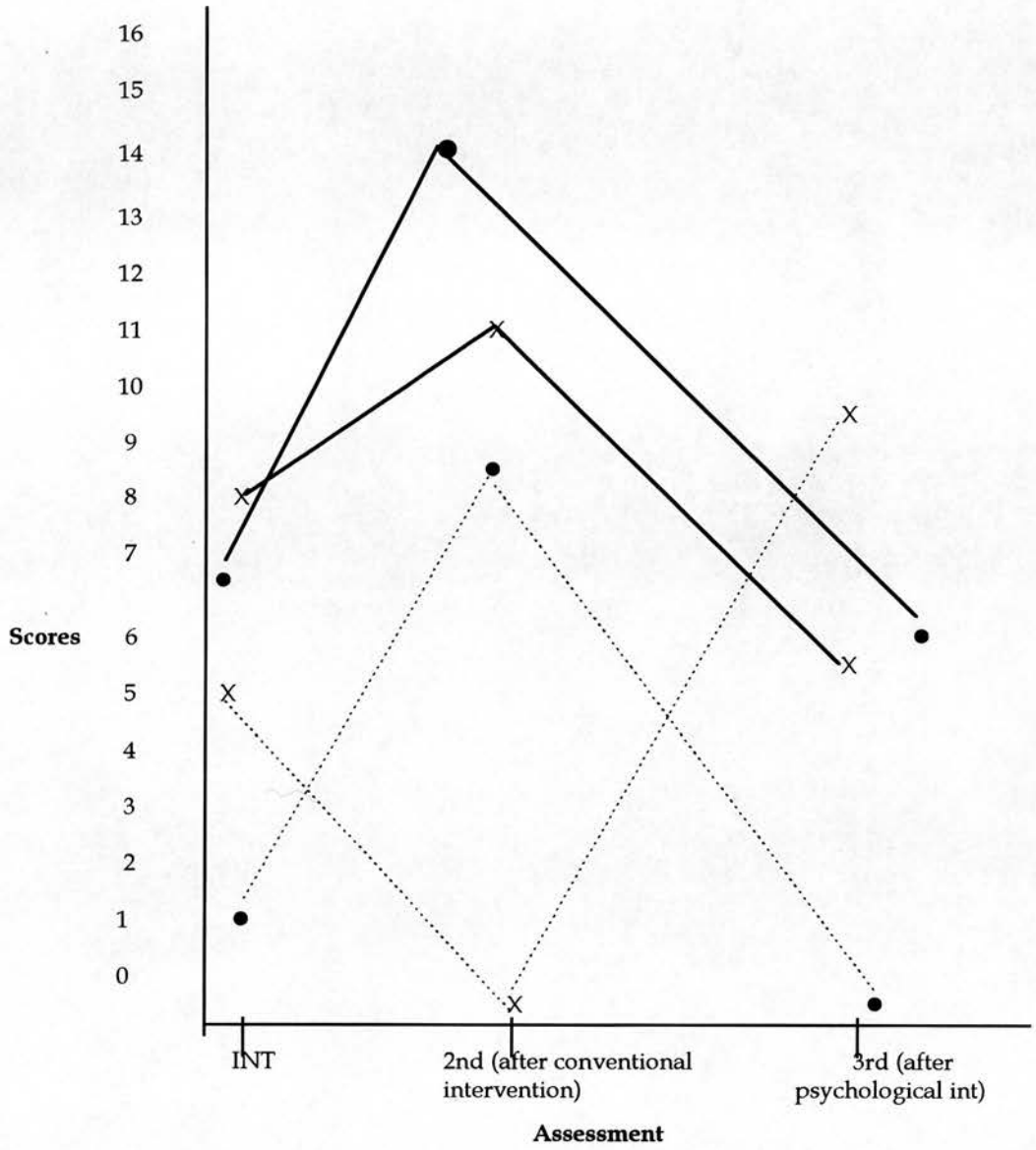
	Assessment		
	1st	2nd	3rd
Active Coping	12	16	16
Planning	13	13	16
Seeking Instrumental Social Support	14	12	12
Seeking Emotional Social Support	11	13	13
Suppression of Competing Activities	14	14	14
Religion	11	11	11
Positive Re-interpretation and growth	4	4	6
Restraint Coping	15	16	16
Acceptance	11	13	14
Focus on and Venting of Emotions	16	14	12
Denial	9	4	4
Mental Disengagement	5	5	5
Behavioural Disengagement	13	14	14
Alcohol/Drug Use	4	4	4
Humour	15	16	16

Table 16 shows the COPE scores for Mrs G before and after conventional and psychological interventions. Following physiotherapy input (second assessment) Mrs G showed an overall improvement in the COPE scores. It was found that she was taking action and exerting efforts to remove or circumvent the stressor (active coping), although thinking about how to confront the stressor or planning how to deal with it remained the same (planning). She showed a reduction in seeking advice and assistance, but was able to obtain or seek sympathy and support from her environment. This would possibly be due to her improved mobility following intervention, which may have increased her level of confidence. There was also an improvement in her ability to hold back emotions (restraint coping) and she was able to ventilate her feelings appropriately. Prior to intervention Mrs G used denial as a form of coping and this type of coping improved following intervention. Her scores also showed that she was able to accept the fact that the stressful event has occurred and that it is real (acceptance).

Following psychological intervention further improvements have been highlighted in the areas of active coping, planning, and acceptance of her condition. Her ability to use appropriate methods of venting her emotions have also been shown.

4.4.4 (i.b.ii) The HAD, GHQ and PCS Scores

Table 17 Mrs G's HAD, GHQ and PCS total Scores before intervention, following physiotherapy and psychological intervention



KEY

• ——— • HAD-A scores

X _____ X HAD-D scores

• ..... • GHQ total scores

X ..... X PCS total scores

Table 17 shows the graphical representation of Mrs G's HAD, GHQ and PCS total scores. The graph shows that following conventional intervention, there is a decrease in the anxiety and depression scores. A similar trend is also noted in the psychiatric caseness (GHQ-T). However, it was found that Mrs G's PCST scores decreased following intervention, indicating a trend towards Mrs G becoming more of an external perceiver. This can be explained by the nature of Mrs G's presentation of problems. However, this improved following psychological intervention. A further reduction in anxiety, depression and psychiatric caseness was observed following psychological intervention.

4.4.4 (i.c) Conclusion

The 7 sessions of psychological intervention have enabled Mrs G to handle her own anger and disappointment. In addition she has learned to cope with her family's anxieties over her disabilities. Mrs G no longer attends the Rehabilitation Unit, but she is aware that she can contact the Unit should the need arise.

4.4.4 (ii.a) Case Study Two

Mrs C is a 55 year old lady diagnosed of MS some 17 years ago. Two years after her diagnosis she retired from her employment because she said that she experienced great difficulty planning, initiating and carrying out her work chores. Following her retirement she spent her days at home working in the greenhouse and attending to her housework. Her husband was kind, caring, supportive, and helpful about the house. This helped Mrs C cope better with the situation. Mrs C's husband unfortunately died suddenly of a heart attack,

which resulted in Mrs C's physical abilities and emotional coping deteriorating. Up until then she only consulted her GP for minor ailments such as influenza, aches and pain. Following her husband's death Mrs C's attendance to her GP increased. In view of the deterioration in her mobility and her ability to undertake household tasks her GP referred her to the Rehabilitation Unit for physiotherapy and occupational therapy input in December of 1994. Mrs C was initially assessed using the assessment tools. Thereafter, she continued to attend for physiotherapy and occupational therapies. During these sessions it was noted by the appropriate staff that Mrs C had been upset on a few occasions and this was due to her inability to accept her husband's death two years prior to her attendance to the Unit. She lived alone but her mother often came to stay with her. There has been conflict between Mrs C and her mother as her mother tends to dominate Mrs C since the death of her husband. This has been one of the issues that Mrs C has been experiencing difficulty coping with.

Mrs C attemped to attend CRUISE after the death of her husband but did not find the attendance there beneficial after one visit. Hitherto she discontinued her attendance there prematurely.

Mrs C attended the occupational and physiotherapy department regularly over a period of six months. There was an improvement in her mobility and she was discharged from occupational and physiotherapy departments. Reassessment was completed. Although the HAD Scale and GHQ did not show a significant caseness (her PLC score highlighted that from having been an internal perceiver she had become an external perceiver) Mrs C's presentation of mood was labile, whereby she would smile one minute and cry the next. In view of this an appointment was arranged for psychological help and Mrs C was seen for the

first time by the Psychologist in mid June of 1995. Mrs C attended and was seen for psychological intervention for seven sessions over a period of six months. The sessions addressed the bereavement and loss experienced by Mrs C, the current disability relating to her poor coping abilities, in addition to learning to cope with the conflict that arose with her mother since the death of her husband. Customised strategy planning was introduced to help Mrs C to deal with her physical disability by using her own strengths to compensate for her specific weaknesses. Effective goal-setting and problem-solving were also included in the sessions, along with stress management approaches . At her last assessment on 13th December 1995 she reported to be more "positive mentally", feeling emotionally well. She was not tearful, and her mood was not labile. The results are as follows.

4.4.4 (ii.b) Results

4.4.4 (ii.b.i) The COPE Scores

Table 18 Mrs C's COPE Scores before and after CRP and following psychological intervention

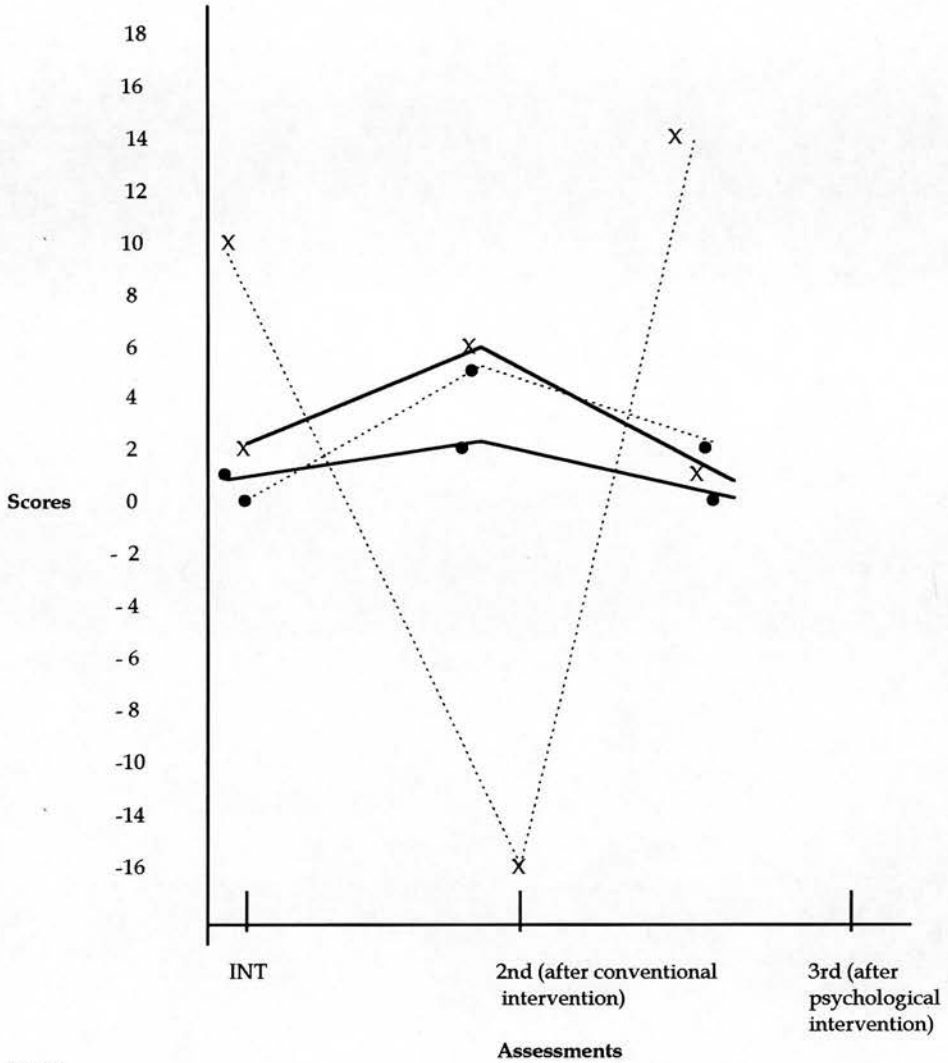
	Assessment		
	1st	2nd	3rd
Active Coping	8	11	14
Planning	9	11	13
Seeking Instrumental Social Support	12	9	9
Seeking Emotional Social Support	11	8	8
Suppression of Competing Activities	10	8	13

Religion	12	7	9
Positive Re-interpretation and growth	13	16	12
Restraint Coping	14	15	14
Acceptance	11	14	12
Focus on and Venting of Emotions	16	12	11
Denial	8	9	9
Mental Disengagement	8	10	11
Behavioural Disengagement	10	9	10
Alcohol/Drug Use	4	4	4
Humour	11	11	11

Mrs C's COPE scores (table 18) highlighted that there have been some changes in some areas of the COPE Scale following conventional rehabilitation programme (CRP). Mrs C was found to be using more active coping in addition to using appropriate planning activities to cope with the stressor following intervention. She was also found to be using less emotional and instrumental support to cope with this. There was a significant decrease in Mrs C's involvement with religious activities after intervention, which may affect her social situation. There was no change in the area of positive reinterpretation and growth after CRP, however, there was a marked improvement in this area following psychological intervention. It was also found that Mrs C was more forthcoming in accepting the fact that the stressful event has occurred and her situation is real. During initial assessment she showed a significant awareness of her emotional distress. This gradually decreased with both the interventions. She was also found to be using more mental disengagement approaches such as distraction techniques, etc, to cope with her stressors.

4.4.4 (ii.b.ii) The HAD, GHQ and PLC Total Scores

Table 19 Mrs C's HAD, GHQ and PLC total scores before and after CRP and psychological interventions



KEY

• ——• HAD-A

X——X HAD-D

• ·····• GHQ-T

X·····X PLCT

Table 19 describes Mrs C's HAD, GHQ and PLC total scores. As can be seen from the graph, Mrs C's PLC total scores have decreased significantly from having been an internal perceiver to becoming an external perceiver following intervention. This could have arisen as a result of therapy and therapist variable. It is also interesting to note that there is an improvement in her GHQ-T, HAD-A and HAD-D. Following psychological intervention, Mrs C's PLC total once again increases, making her an internal perceiver.

4.4.4. (ii.c) Conclusion

Mrs C has been in touch with several voluntary organisations since her discharge from therapy, which has been occupying her time. Periodically she attends for a follow-up appointment with the rehabilitation physician.

4.4.5 Conclusion

In summary, the PCS could be used in Rehabilitation Programme planning to identify patients' perceptions of their illness and their coping abilities. Altering these perceptions by interventions addressing these issues such as Stress Innoculation and Coping Flexibility approaches will be beneficial in the successful outcome of rehabilitation programmes.

4.5 Implications of Findings

The findings from this study have implications for health care professionals who work with chronically ill patients in rehabilitation units such as Occupational Therapists, Physiotherapists, and Clinical Psychologists. A substantial number of patients attend rehabilitation units who are external

perceivers or copers and these individuals go unidentified. Rehabilitation for these patients produces little positive outcome. For the patient this results in deterioration of coping abilities, disappointments, depression and anxiety (Murray, 1993).

Routine use of the PCS and the HAD can identify individuals who are external perceivers and also assess their levels of anxiety and depression. This can then facilitate discussions about the progress in the patient's rehabilitation outcome both with MS patients as well as with other chronically ill patients.

Since completing the development of the scale the PCS has been used in a Chronic Pain Management Programme. The Chronic Pain Management Programme is a two year Pilot Research Programme funded by the Scottish Home and Health Department. The PCS is validated against some of the relavent scales used in the Pain Research Programme with a view to determining the predictive nature of the PCS, with a different group of subjects with a chronic disease. With this group of subjects the intervention is a multi disciplinary group approach including a cognitive behavioural approach which will enable us to discover if such approaches do produce a desired outcome in patients with chronic pain.

As recently as 1995, Stenager et al reported that non-medical treatment did not alter the course of MS. This does not mean that non-medical treatment does not alter the way of coping, enriching the quality of life. The findings of this study also have implications for the development of psychological treatment strategies for external perceivers. Psychological therapies have been shown to be effective in changing patients perceptions . The aim of psychological approaches is to alter the perception in order that individuals become more internal perceivers

and attempt to take control of their situation. There is some data now available on this study. An attempt has been made to provide some evidence for this in the next chapter.

Emotional disturbances in people suffering from physical disease are common and there is evidence to suggest that these are related more to cognitive factors than to severity of symptoms or disorder (Sensky 1990). Cognitive-behavioural interventions have been shown to be successful in the management of these cognitive factors (Sensky 1993).

Researchers and investigators who have used cognitive therapy as a treatment approach for psychological difficulties related to medical patients have reported positive encouraging results. Cognitive therapy has been used successfully with cancer patients with pain (Dalton and Lambe, 1994); mastectomy patients (Tarrier & Maguire, 1984); asthma (Maes and Schlosser, 1988); inflammatory bowel disease (Schwarz and Blanchard, 1991); in the management of chronic pain and migraine headaches (Newton-John, Spence and Schotte, 1995); with patients suffering from chronic fatigue syndrome (Surawy, Hackman, Sharpem, 1995); and with patients suffering from chronic obstructive airways disease (Atkins, Kaplan, Timms, Reinsch and Lofback, 1984). Cognitive approaches have also been shown to be effective in selective patients who suffered myocardial infarction or from angina (Lewin et al, 1994).

Up to date literature search in the area of cognitive-behaviour therapy intervention with MS highlighted only one study by Larcombe & Wilson (1982). Their results clearly support the use of cognitive-behavioural treatments for depression in this group of population.

A new research proposal is underway at the Douglas Grant Rehabilitation Unit at Ayrshire Central Hospital , Irvine, to ascertain the role of psychological intervention especially cognitive behavioural intervention on a one to one basis with MS patients who develop psychological distress.

4.5.1 Future Research Implications

The findings of this study suggest various possibilities for future research. As already mentioned, the use of the PCS as a clinical tool will identify patients with external perceptions; psychological interventions with these patients can be researched further.

The predictive validity of the PCS has not been fully established. This could be done by administering the PCS to subjects during their initial attendance at rehabilitation programmes; reassessed post rehabilitation and a follow up assessment being carried out at a later date. This is to determine whether the scale has the ability to predict psychological and psychiatric morbidity. It will be necessary to administer the scale to a larger sample of subjects. The present study used only twenty subjects and the full predictive validity is limited. Although the scale appears to be reliable, the PCS is in its developmental phase and should improve with further use and refinement. Since the completion of the study, colleagues from a Glasgow Rehabilitation Unit have requested to use the PCS with their patients in the community. This will provide further information about the scale, i.e., use of the scale with different population.

It would be appropriate for future research to consider assessing the levels of disability objectively rather than considering only the physician`s opinion.

This can best be carried out by the use of standarised measures of disability, such as the Expanded Disability Status Scale, which incorporates the three effects of disease; impairments, disabilities and handicaps. Further emphasis should also be made to validate the PCS, using other established measures such as the Life Orientation Test by Scheir et al (1985), the Self-Esteem Scale by Rosenberg (1965) and the Hopelessness Scale by Beck, Lester and Trexler (1974). These type of scales measure personality characteristics that are related to perception of coping although none of these characteristics are synonymous with perception of coping.

4.5.2 Limitation of the Present Study

The generalisability of the findings of the second part of the study are somewhat limited for two main reasons, the first being this study only used 20 subjects. This is a small sample, larger sample size would have been more desirable. Statistically this have implications on significance of results. Secondly, the findings apply only to patients who presented themselves to the rehabilitation unit, all of whom participated in the research project, thus creating a selection bias and limiting the external validity of the research finding.

The second part of the study also involved the interviewer reading the assessment measures and the subjects requiring to indicate which response they felt was most appropriate. One should be cautious in the interpretation of those results. There is a possibility that this type of approach may give rise to possible response bias.

4.6 Conclusion

Despite these limitations, the present findings provide encouraging initial support for the PCS. The intention from now on would be to validate the scale further using other appropriate measurement tools such as those mentioned above, with different chronic populations and refining the scale. Discussions for further research are currently in progress addressing these issues.

5. FURTHER VALIDATION OF PCS---THE PAIN PROJECT

5.1 Overview

The purpose of this chapter is to provide further validity of the PCS and show some evidence for the effectiveness of a multidisciplinary cognitive behavioural approach in the management of chronic pain. This chapter is therefore intended to be brief. Initially this was to be attempted with a group of MS patients attending the Rehabilitation Unit, but due to difficulty recruiting a desirable number of subjects within a given time, it was decided that the patients who were already waiting to take part in the multi-disciplinary chronic pain management programme would be considered. This project was funded by the Chief Scientist Office of the Scottish Home and Health Department and the project was intended to run for two years. The aim of the project is to investigate the efficacy of an out-patient multi-disciplinary, cognitive behavioural group programme for the rehabilitation of patients with chronic pain while at the same time attempting to validate the PCS further.

5.2 Introduction

Chronic pain is a growing problem. In a 1990 survey of a thousand adults in Britain (Rigge, 1990) 11.5% were found to suffer from chronic pain. 55% of these were unable to work or lead a normal life because of pain. In addition, 17% had retired and 6% were housebound by pain. 70% remained in pain despite taking analgesics.

In 1994, the Department of Health carried out a survey of six thousands adults and found 40% of the survey had experienced back pain in the previous twelve months and over 10% had found that they were unable to lead a normal life.

Frank (1993) in his report postulated that back pain was the biggest single cause of sickness absence from work with 52.6 million days lost in 1988 to 1989. This accounted for 12.5% of the total working days and had an estimated cost of £2000 million. In addition back pain was the reason for estimated two million General Practitioners consultations annually, 300,000 hospital out-patient consultations and 100,000 hospital in-patient episodes. It was also estimated by Frank that in an average health district of 250,000 population there will be up to 1000 people severely affected by back pain.

Many patients with chronic non-malignant pain referred to out-patient pain clinics do not respond to classical intervention methods of pain relief. For these patients there is no tablet, injection or operations which provide a 'cure'. The only hope for these patients is to reverse the devastating effects of their chronic pain which can become self-perpetuating and highly destructive to their life-style. This can be achieved by a cognitive behavioural treatment programme.

The current pain management programme is a multi-disciplinary group programme encompassing a cognitive-behavioural approach; the aim of the programme is not to cure the pain, but to restore reasonably normal functioning despite the pain. This involves increased activity, fewer pain behaviours and improvement in depressive and anxiety symptoms.

5.3 Methodology

Prior to starting this study ethical approval was obtained from the ethical committee of Ayrshire and Arran Health Board.

5.3.1 Subject Selection.

Subjects were selcted from referrals to the Pain Relief Clinic. The criteria for selection were that the subjects were to be aged between 18 and 70, with a major continuing disability from non-cancer pain; both the patients and their General Practitioners must accept that this is the end of the line and that all the necessary investigations are completed and quests for a cure have been exhausted. The other criteria included, no past history of serious mental illness and no learning difficulties, the ability to make their own way to the programme at the Douglas Grant Rehabilitation unit at Ayrshire Central Hospital, Irvine, and no active involvement in litigation. The subjects were also expected to be fluent in English language.

5.3.2 Assessment Measures

The subjects were assessed using the following measures:

1. The Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) (HAD Scale); details of this Scale have already been described in Chapter Two of this Thesis. (Appendix 2).

2. West-Haven-Yale Multi-Dimensional Pain Inventory (Kerns, Turk and Rudy, 1985) (WHYMPI). This inventory is a 52 item inventory divided into three parts with a total of twelve sub-scales which examine the impact of pain on patients' lives, the responses of others communication of pain and the extent

to which patients participate in common daily activities. The WHYMPI is an integrated tool for measuring the emotional, cognitive and behavioural aspects of pain. This is a brief self administered inventory designed to be used in the context of a multidimensional assessment of chronic pain. This is a commonly used assessment tool in Pain Management Programmes. (Appendix 5). The reliability estimates for all the twelve subscales appear to be quite satisfactory, ranging from 0.70 to 0.90. The stability co-efficients are in the 0.62 to 0.91 range indicating that a substantial proportion of the reliable variance is stable over time.

3. The Pain Related Self-Statement Scale (PRSS) and the Pain Related Coping Scale (PRCS) (Flor, 1992). The PRSS assesses situation specific aspects of patients' cognitive coping of pain. This scale consists of two sub-scales. These are: catastrophising and coping. The PRCS measures general attitudes towards pain, and again consists of two sub-scales, helplessness and resourcefulness. (Appendix 6, 7). The two scales (PRCS and PRSS) are reported to assess the cognitive schemata (PRCS) and automatic thoughts (PRSS). Cognitive schemata refer to cognitive structures that contain the individual's stored knowledge about the world and how the individual interprets environmental events. The PRCS therefore, assesses underlying beliefs of the pain controllability and predictability. In contrast the automatic thoughts refer to things people say to themselves in a given situation i.e self-statements. These are said to be guided by underlying schemata. Therefore, the PRSS is intended to assess situation specific cognitions that either promote or hinder attempts to cope with pain. The reliability estimates for PRSS subscales are 0.92 and 0.88 and for PRCS are 0.83 and 0.77. The stability co-efficients are 0.87 (PRSS-catastrophising), 0.77 (PRSS-coping), 0.86 (PRCS- helplessness) and 0.88 (PRCS-resoursefulness). These scales are reasonably stable.

4 The PCS--currently developed scale.

5.3.3 Procedure

The subjects for the programme were initially seen by the anaesthetist who assessed the general suitability of the individuals to be included in the study. Those patients who did not wish to be included in a group programme were seen at the routine out-patient clinic. The Clinical Psychologist then selected the subjects for the study using the above criteria. Those who did not comply with the selection criteria were not included, instead they were also seen on a one-to-one basis at a routine out-patient clinic.

The subjects who were selected for the study were assessed using the measures mentioned in the previous section. They were then informed that there was a waiting list for this group and they would be contacted as soon as the group was due to start. This measure formed the waiting time assessment. All the subjects waited for a minimum period of twelve weeks and this waiting time was used as a control period. The reason for this procedure was that, recruitment of subjects for this study was anticipated to be slower; therefore if the same subjects formed the control group by being on the waiting list then it was thought that this would solve the problem. By adopting this approach, it was also thought that the ethical issue of the control group not receiving the multi-disciplinary intervention input would also be solved.

As soon as a date for the commencement of the group programme was decided, the subjects who were waiting in the waiting group for twelve, and longer than twelve weeks, were contacted. They were once again asked to complete the same assessment measures. This then formed the pre-intervention measure. Following this assessment the aims of the group and the procedure of the sessions were explained individually and a date for the commencement of the

group was established. The subjects then passed through the programme in groups of eight to fifteen over a period of ten weeks for three hours per week. At the end of the ten week programme the subjects were requested to complete the same assessment tools that they completed during the waiting time and before the programme began. This constituted the post intervention assessment. At this point the subjects were also given a course evaluation questionnaire. The details of this will not be discussed in this chapter. They were also informed that the anaesthetist would contact them by post for a follow-up evaluation at six months, and again at a year after completion of the programme.

5.3.4 The Multi-Disciplinary Programme

The programme team consisted of a clinical psychologist, a physiotherapist, an occupational therapist and an anaesthetist. The anaesthetist attended the first meeting and thereafter during the mid programme to discuss the role of medication and clarify any other medical issues that the subjects raised. At the last meeting again the anaesthetist was present to answer medical queries raised by them.

The physiotherapist's role in the programme was to teach a graded exercise programme, setting realistic goals for exercise, functional activities and reinforcing the gains of planned activity to help them "push" through the 'pain barrier'. The occupational therapist worked in a similar way to the physiotherapist but emphasis was placed on goal setting and pacing of activities, in addition to enabling the subjects to change the environment, to reduce their disability and increase independence. The clinical psychologist's role was to provide insight into their problems and to reverse the psychological factors that contributed to chronic pain symptoms. This was achieved by using a cognitive behavioural approach.

5.4 Results

5.4.1 Introduction

Data collection for the pain management programme started in November of 1995 and is continuing. Subjects seen until December of 1996 are included in the current analysis. Four groups of subjects have so far taken part in the programme. The first group consisted of 9 subjects, second group 11 subjects, third group 8 subjects and the fourth group 13 subjects. Two subjects from the first group, three subjects from the second group, three subjects from the third group and five subjects from the fourth group failed to complete the programme. This represents a 32% drop out. The remaining 28 subjects completed the 10 week programme. There were 15 males (54%) and 13 females (46%) in this sample; the mean age of the population was 48.32 years (SD 8.02).

The data was analysed using the PC version of the SPSS package. The main analyses carried out were the Pearson Product Moment Correlation, the McNemar test, within group repeated measures analyses of variance, and the Tukey Honestly Significant Difference test to ascertain post hoc differences.

5.4.2 PCS Correlation with the other scales

The PCS was evaluated against the WHYMPI, PRSS, PRCS, HAD-A and the HAD-D scales. Significant correlations of $P=< 0.05$ (two tailed) are presented in

bold italic script. The numbers in brackets in the table denote the number of cases. The number of responses for the WHYMPI "support" subscale and all the subscales of the part two of the WHYMPI were fewer than the responses for the rest of the subscales. This is because these individuals were living alone and did not complete these subscales.

Table 20 Pearson Product Moment Correlation Co-efficient-- PCS with the other scales

	PCS		
Variables	**component 1**	**component 2**	**component 3**
WHYMPI Part 1			
Interference	-.1374 P=.486	-.2040 P=.298	-.1967 P=.316
Support	-.1014 (23) p=.645	-.1240 (23) P=.573	.0960 (23) P=.663
Pain Severity	*-.3728* *P=.051*	***-.4463*** ***P=.017***	-.2511 P=.197
Self Control	***-.6192*** ***P=.001***	***-.4185*** ***P=.027***	***-.4265*** ***P=.024***
Neg Mood	-.0594 P=.764	-.1132 P=.566	-.0830 P=.675
WHYMPI Part 2			
Punishing responses	-.0567 (24) P=.793	-.2329 (24) P=.273	.0356 (24) P=.869
Solicitors responses	*-.3764* (24) *P=.070*	*-.3779* (24) *P=.069*	-.1139 (24) P=.569
Distracting responses	-.0671 (24) P=.755	-.0980 (24) P=.649	.2825 (24) P=.181
WHYMPI Part 3			
Household chores	.2303 P=.238	-.0253 P=.898	.2871 P=.139
Outdoor work	-.0009 P=.997	-.0524 P=.791	.0196 P=.921

Activities away from home Social activities	.1584 P=.421 .3154 P=.102	.1736 P=.377 .2368 P=.225	.1126 P=.568 .3083 P=.110
PRSS Catastrophising Active coping PRCS Helplessness Resourcefulness	***-.5729*** ***P=.001*** .3703 P=.052 -.2201 P=.260 .2800 P=.149	***-.5485*** ***P=.003*** ***.5590*** ***P=.002*** ***-.5585*** ***P=.002*** *.3351* *P=.081*	***-.5088*** ***P=.006*** ***.3980*** ***P=.036*** -.2233 P=.253 -.0038 P=.985
HAD - A	-.1213 P=.539	-.1323 P=.502	.1574 P=.424
HAD - D	-.1468 P=.456	-.0628 P=.751	-.0166 P=.933

The PCS did not correlate significantly with many of the WHYMPI subscales nor the PRCS but significant correlations were found with the PRSS subscales as shown in table 20. No significant correlations were found with the HAD anxiety and depression scales.

5.4.3 TheMean and standard deviation of all scales

Table 21 Means and Standard Deviations of all variables for waiting, pre-treatment and post-treatment assessments

Variable	Waiting Assessment		Pre-treatment assessment		Post-treatment assessment	
	Mean	SD	Mean	SD	Mean	SD
HAD - A	11.79	3.96	11.54	3.91	8.50	2.83
HAD - D	11.14	2.68	11.11	2.91	8.50	2.60
WHYMPI Part 1						
Interference	46.36 (29-56)	8.48	46.18	8.71	40.43	4.35
Support	17.09 (11-21)	3.85	17.09	3.85	16.00	3.06
Pain severity	18.21 (11-21)	2.50	18.18	2.57	15.50	3.38
Self control	8.85 (8-14)	2.96	8.81	3.03	7.00	2.16
Negative mood	16.43 (12-21)	3.33	16.32	3.37	11.89	2.71
WHYMPI Part II						
Punishing responses	11.04 (13-24)	3.96	11.21	4.38	9.17	3.75
Solicitous responses	22.21 (18-36)	6.28	22.50	6.16	20.04	4.35
Distracting responses	10.96 (1-12)	3.54	11.29	3.65	11.54	2.95
WHYMPI Part III						
Household chores	15.61 (16-30)	6.62	15.61	6.62	17.75	5.89
Outdoor work	7.19 (1-15)	3.00	6.93	3.02	8.71	3.15
Activities away from home	10.61 (1-!2)	3.50	10.39	3.72	12.14	3.69

Social activities	11.96 (1-12)	3.57	11.82	3.68	13.29	4.19
PCS	3.54	5.29	3.11	5.85	6.89	4.29
PRSS						
Catastrophising	23.21 (23-45)	7.14	23.86	7.66	17.64	6.28
Coping	19.07 (0-22)	4.94	19.46	5.15	24.82	5.28
PRCS						
Helplessness	17.29 (18-35)	6.60	17.75	6.79	13.79	5.37
Resourcefulness	25.93 (0-20)	6.05	25.18	6.73	28.96	4.63

Table 21 highlights a change in the mean and standard deviation scores at post treatment in all measures. The numbers in bracket denote the range of scores for caseness.

5.4.4 PCS intervention analyses

Table 22 PCS total scores - Control, pre and post intervention

Variable	Waiting Assessment		Pre-intervention		Post-intervention	
	Score of =< 0	Score of =>1	Score of =< 0	Score of =>1	Score of =< 0	Score of =>1
PCS total	8	20	9	19	1	27

Table 22 shows, 8 subjects to be external perceivers at waiting and 9 subjects to be external perceivers pre-intervention assessments. At post intervention assessment there was only one. This shows a positive trend. The mean PCS

score pre intervention was 3.11 (SD =5.85) and post intervention was 6.89 (SD =4.29) as shown in table 21. Analysis of variance results are shown in table (22i).

Table 22i PCS - Analysis of Variance within subject effect

Source of Variation	Sum of Squares	df	Variance	F	Sig of F
Within & Residual	291.33	54	5.40		
PCS	240.67	2	120.33	22.30	.000

Table 22(i) shows a significant difference between the three groups. In view of the significant results the post hoc comparison was carried out which revealed that the significant differences were between the waiting and post intervention assessments, and the pre and post intervention assessments rather than the waiting and pre intervention assessments (T 0.01=1.88; M1-M2, M3-M1, M3-M2 = 0.43,3.35 and 3.78 respectively)

Table 22ii McNemar test for the significance of change

		Pre-intervention	
		Internal	External
Post-intervention	Internal	19	7
	External	0	2

The McNemar test was carried out to assess the significance of change between the two groups pre and post intervention. The result was significant (obtained Chi-square score was 5.1 and the expected Chi-square score is 3.84, $P<0.05$ two tailed).

5.4.5 HAD scale analyses -Anxiety scores

Table 23 HAD-A Scores waiting, pre and post intervention assessments

Variable	Waiting assesment		Pre-intervention assesssment		Post-intervention assessment	
	Scoreof =<10	Scoreof =>11	Scoreof =< 10	Scoreof => 11	Scoreof =< 10	Scoreof => 11
HAD - A	13	15	12	16	21	7

Table 23 highlights that 15 subjects at waiting assessment and 16 subjects at pre intervention assessment to show caseness for anxiety i.e. obtaining scores of =>11. At post intervention assessment this was 7, a reduction in anxiety. The mean score of the subject sample on the anxiety subscale of the HAD before intervention was 11.54 (SD=3.91). The mean score post intervention was 8.50 (SD=2.83) (table 21).

Table 23i - HAD - A Analysis of Variance with in subject effect

Source of Variation	Sum of Squares	df	Variance	F	Sig of F
Within and Residual	309.98	54	5.74		
HAD - A	187.36	2	93.68	16.32	.000

Analysis of variance (table 23i) shows a significant result. The Tukey test showed a significant change between the waiting assessment and post assessment , and pre assessment and post assessment (T 0.01=1.96; M1-M2, M3-M1, M3-M2=0.25, -3.29and -3.04 respectively).

Table 23ii Pre-intervention - anxiety and PCS scores

	Caseness	Non-caseness
Internal	5	2
External	12	9

The Chi-square tests were attempted, to ascertain the number of Internals who showed caseness and non-caseness, and the number of Externals who showed caseness and non-caseness, for anxiety, pre intervention and post intervention. The obtained results pre intervention (Chi-square = 0.44) and post intervention (Chi-square = 0.77) were non significant (tables 23 ii and iii).

Table 23iii Post intervention anxiety and PCS scores - the relationship

	Caseness	Non Caseness
Internal	2	10
External	5	11

5.4.6. HAD Scale analyses-- Depression scores

Table 24 HAD-D - Scores--- Waiting, Pre and Post intervention

Variable	Waiting		Pre-intervention		Post-intervention	
	=< 10	=>11	=< 10	=> 11	=< 10	=> 11
HAD - D	16	12	15	13	24	4

Table 24 shows 12 subjects during waiting assessment and 13 subjects at pre assessment to show caseness for depression (scores of =>11). At post intervention this was reduced to four subjects. The mean score pre intervention was 11.11 (SD=2.91) and post intervention was 8.50 (SD=2.60) (table 21)

Table 24i HAD - D - Analysis of variance within subject effect

Source of Variation	Sum of Squares	df	Variance	F	Sig of F
Within & Residual	111.36	54	2.06		
HAD - D	128.64	2	64.32	31.19	.000

Analysis of variance showed a significant outcome and as before the Tukey test highlighted that significant changes were noted between the waiting assessment and post intervention assessments and pre intervention and post intervention assessments (table 24I) (T 0.01=1.71; M1-M2, M3-M1, M3-M2=0.03, -2.64 and -.2.61 respectively).

Table 24ii Pre-intervention - depression and PCS Scores- the relationship

	Depression	
	Caseness	**Non-Caseness**
Internal	2	5
External	11	10

Table 24iii Post-intervention depression and PCS scores- the relationship

	Depression	
	Caseness	**Non-Caseness**
Internal	1	11
External	3	13

The Chi-square tests were carried out on the above two tables to ascertain the number of Internals who showed caseness and non-caseness and the number of externals who showed caseness and non-caseness for depression pre and post intervention. The results were non significant; the obtained pre intervention

result was 1.2 and the obtained post intervention result was 0.54.

5.4.7 WHYMPI, PRSS and PRCS analyses

The mean and standard deviation of the WHYMPI, PRSS and the PRCS are highlighted in table 21. Table 25 below shows the Analysis of Variance results on all the 12 subscales of the WHYMPI and the two subscales of the PRSS and the PRCS.

Table 25 Analysis of variance - of WHYMPI, PRSS and PRCS

Variables	Sum of squares	df	Variance	F	Sig of F
WHYMPI Part 1					
Interference	1459.74	54	27.03		
	639.93	2	318.46	11.78	.0001
Support	64.55	44	1.42		
	18.12	2	9.06	6.37	.004
Pain severity	112.93	54	2.09		
	135.74	2	67.87	32.45	.0001
Self control	278.10	50	5.56		
	54.56	2	27.28	4.91	.011
Neg mood	144.17	54	2.67		
	375.17	2	187.58	70.26	.0001
WHYMPI Part 2					

Punishing responses	83.64	46	1.82		
	61.69	2	30.85	16.97	.0001
Solicitous responses	408.75	46	8.89		
	86.58	2	43.29	4.87	.012
Distracting responses	75.89	46	1.65		
	4.11	2	2.06	1.25	.297
WHYMPI Part 3					
Household chores	140.95	54	2.61		
	85.71	2	42.86	16.42	.0001
Outdoor work	90.72	52	1.74		
	56.62	2	28.31	16.23	.0001
Activites away from home	124.31	54	2.30		
	51.02	2	25.51	11.08	.0001
Social activities	124.17	54	2.30		
	36.50	2	18.25	7.94	.001
PRSS					
Catastrophising	644.67	54	11.94		
	654.00	2	327.00	27.39	.0001
Active coping	547.45	54	10.14		
	577.88	2	288.94	28.50	.0001
PRCS					

Helplessness	652.98 263.02	54 2	12.09 131.51	10.88	.0001
Resourcefullness	649.64 225.02	54 2	12.03 112.51	9.35	.0001

Except for one subscale -distracting responses- all the remaining variables show significant results at P<0.05 levels. Tukey tests were carried out on all the significant results as shown in table 25i.

Table 25i WHYMPI, PRSS and PRCS --waiting, pre and post intervention mean differences, and T-values.

	PRE1-PRE2 (M1-M2)	POST-PRE1 (M3-M1)	POST-PRE2 (M3-M2)	T-value	Sig.level
Interference	0.18	-5.93	-5.75	4.24	0.01
Support	0	-1.09	-1.09	0.85	0.05
Pain severity	0.03	-2.71	-2.68	1.18	0.01
Self-control	0.04	-1.85	-1.81	1.58	0.05
Negative mood	0.11	-4.54	-4.43	1.33	0.01
Punishing. responses	-0.17	-1.87	-2.04	1.25	0.01
Household chores	0	2.14	2.14	1.32	0.01
Outdoor work	0.26	1.52	1.78	1.09	0.01
Activities away from home	0.22	1.53	1.75	1.23	0.01

Social activities	0.14	1.33	1.87	1.23	0.01
Catastrophising	-0.65	-5.57	-6.22	2.83	0.01
Coping	-0.39	5.75	5.36	2.05	0.01
Helplessness	-0.46	-3.5	-3.96	2.83	0.01
Resourcefulness	0.75	-3.02	-3.78	2.83	0.01
Solicitous responses	-0.29	-2.17	-2.46	2.05	0.05

5.5 Discussion

5.5.1 Introduction

One of the aims of this chapter was to establish the validity of the PCS against the other scales, another was, the effectiveness of a cognitive behavioural approach in the management of chronic pain. In an effort to establish the validity of the PCS, it was administered to a group of chronic pain subjects, along with a number of different scales. Included among these other scales were, a measure of anxiety and depression (Zigmond and Snaith, 1983), Kerns et al's (1985) Multidimensional Pain Inventory and a measure of pain-related cognitions (Flor et al, 1992).

5.5.2 Correlation of the PCS

The correlation of the PCS against the other scales showed no significant results except for the PRSS. Catastrophising and active coping are subscales of the PRSS and these subscales correlated with all components of the PCS.

Catastrophising correlated negatively while active coping positively with all the three components. Helplessness and resourcefulness are subscales of the PRCS; helplessness correlated negatively with component two but resourcefulness failed to show significant correlation. The concepts, catastrophing, active coping, helplessness and resourcefulness are all important variables that play a part in perception (Flor et al, 1993) of coping. Although it is important for any newly developed scale to correlate with other scales, it is equally important that the strength of these relationships are not too strong, as this will question the need for a scale like the PCS. The magnitude of the correlations obtained with the PCS were not strong. Therefore, it can be again emphasised that the PCS is measuring a new concept that the other scales are not addressing hence, the poor correlations. The other interpretation for the small correlations is measurement error. The WHYMPI measures the emotional, cognitive and behavioural aspects of pain. These scales do not address the perception of pain. Measures such as the Life Orientation Test and Self-Esteem Scale may address this. However, further data are needed in order to be certain about this emphasis.

5.5.3 Intervention outcome

The PCS analysis showed a significant positive change in individuals between waiting and post assessment, and preassessment and post assessment. 75% of the subjects were found to be external perceivers whilst waiting to enter the programme and pre intervention. For these individuals, pain coping was perceived to be outwith their control. Following intervention, this reduced to 48%, indicating cognitive behavioural intervention being effective in changing perception in the positive direction. This result is in line with the findings of Luscombe, Wallace, Williams and Griffiths (1995). They found that following a

cognitive behaviour therapy pain management programme, an increased number of their subjects had good control of their pain and were taking personal responsibility for their pain.

It was found that 53% of the subjects reported anxiety symptoms at waiting time assessment and 57% at pre treatment assessment. Following intervention this was 25%; 75% reported being anxiety-free post intervention. Similarly 42% and 46% reported depressive symptoms during waiting assessment and pre treatment assessment. This was reduced to 14% following intervention; 86% reported to be "depression free" following intervention. It is also important to point out that 80% of the subjects were on antidepressant medication prior to consulting the anaesthetist and starting the programme. As they were already on antidepressants before starting the programme it can be presumed that the programme was responsible for the improvement in anxiety and depression in these subjects. Improvement in depression rating has been a common aim and frequent outcome of cognitive behavioural approaches to pain management (Turk et al,1983). The assumption here is that improvement in mood will enable everyday activities to be pleasant and potentially rewarding especially in the areas of work, social and leisure pursuits thus improving the pain coping. This trend was noted with this group of subjects.

Chronic pain is a complex, subjective phenomenon, that is uniquely experienced by each patient. Therefore subjective evaluation of the pain experience is important in the patient's perception of pain, and the management of it by themselves and others. The first part of the WHYMPI evaluates the five important dimensions of the pain experience. These are; perceived interference of pain in various areas of their functioning, support and concern of significant others, pain severity, self control and negative mood. 27 subjects reported there being a problem in the perceived interference of pain in various areas of their

functiong pre and post intervention. This did not change following cognitive behavioural programme. All the subjects reported pain severity being a problem before intervention and 24 subjects reported pain severity being a problem post intervention. 13 subjects pre intervention and six subjects post intervention reported control being an issue. Negative mood was reported by 23 subjects preintervention and by 9 subjects post intervention. These five scales represent distress dimension, as predicted by the negative mood which improved following cognitive-behavioural intervention, this in turn improving self control scores.

The second part of the WHYMPI examines the responses of significant others to communication of pain. Four subjects reported there being no significant others in their lives to communicate their experience of pain. 8 subjects pre intervention and four subjects post intervention reported that their pain was punishing. 20 subjects pre intervention and none post intervention reported solicitous responses. 14 subjects pre intervention and again the same number of subjects post intervention reported distraction as a problem. These subscales measure the perceived responses of others on demonstration of pain. The results of these three scales provide important information on the social contingencies for pain, instrumental behaviour, dependency, mood and the subjective experience of pain.

The third part of the WHYMPI examines the subjects' reports of their participation in four common daily activities. These are household chores, out door work, activities away from home and social activities. 15 subjects pre intervention and 17 subjects post intervention found household chores a problem. 28 subjects found out door work to be problematic pre intervention and 25 subjects post intervention found this to be the case. 21 subjects pre intervention and 18 subjects post intervention found activities away from home

a problem; 19 found social activities a problem before intervention and 15 a problem post intervention. This type of result is not uncommon in view of chronic pain being a debilitating and restrictive condition. Another possible explanation for this type of result is time. Post intervention assessments were carried out on the 10th session of the programme and it is likely that the subjects were not well adjusted to the pacing and goal setting tasks of the programme by then.

Theoretically the scales of the WHYMPI are linked to the cognitive - behavioural perspective, placing emphasis on the assessment of the subjective distress experienced by the patients in terms of pain suffering and distress and the impact of this on the various aspects of the patients' lives. Associated with this perspective is the individuals perception of self control and problem solving abilities. The multi-disciplinary cognitive-behavioural therapy programme attempted to address these as has been shown by the statistical analyses (analysis of variance).

The PRSS and PRCS were administered along with the WHYMPI. It is recommended by Flor, et al (1993) that the PRSS and the PRCS are administered along with a multidimentional assessment measure . This is in order that the two scales can yield useful information regarding pain, especially in the pain -- depression relationship. It was hypothesized by Flor et al that persons with a helpless attitude towards their pain and more negative self statements would experience more pain and interference as well as lower life control. The concepts, catastrophising, coping, helplessness and resourcefulness are all cognitions related to depression. In this study 15 subjects pre treatment and six subjects post treatment reported significant problem in the area of catastrophising while 18 subjects reported not coping pre treatment and only four subjects reporting this post intervention. With the helplessness subscale, 14

subjects reported this being a problem pre intervention and five post intervention. Only three individuals found that they had a problem with resourcefulness and this was not a problem post intervention. Major improvements were noted in the PRSS and the PRCS subscales indicating cognitive behavioural approaches being effective.

Chi-square statistical analysis is the next step but this is not intended for the purpose of this chapter. However Analyses of variance were carried out on all the scores; these have yielded significant results (except for one subscale). The Tukey Honestly Significant Difference Test highlighted that significant changes were noted at the waiting and post intervention assessments and pre and post intervention assessments. These results show that a multidisciplinary cognitive behavioural intervention is a constructive way of improving management of chronic non malignant pain.

It is also important to reiterate here that sample size is a vital factor; out of 41 patients assessed initially for the group programme, only 28 patients completed the programme. This was a 32% dropout; Luscome et al (1995) reported a 25% drop out in their study. One of the inclusion criteria is that subjects are able to make their own way to the programme at the Douglas Grant Rehabilitation Unit. This may have posed a problem, but, since there were other subjects in this study who travelled as far away as Glasgow to attend these groups at the Douglas Grant Rehabilitation unit.

Despite these concerns data collection will continue. The subjects who have completed the programme are advised to attend the pain management support group organised by the ex-group members. This is to ensure continuing support.

5.6 Conclusion.

The results of the present pain study show that despite the small sample size, the PCS has shown some correlation with the PRSS subscales. Generalisation of this result at this point in time is premature and inappropriate. Data collection for this purpose will continue and the PCS will be correlated again at a later date with a larger sample size.

With regard to the application of cognitive behavioural methods to chronic pain patients as a method of intervention, the assumption has generally been that these methods should aim to increase the use of positive coping strategies (Turk, Meichenbaum and Genest, 1983). Discussions with pain patients often suggest that they are already using positive strategies, but their use may often be unrelated to the severity of the pain problem. Therefore the aim of this multidisciplinary cognitive behavioural programme was to reduce the frequency of the use of negative strategies, and instead to increase the rate of the positive strategies. Both Chaves and Brown (1978) and Rosenstiel and Keefe (1983) agree with such a view as they say that successful coping is a consequence of avoiding catastrophising cognitions; reduction in catastrophsing significantly reduces pain intensity and physical disability. This can only be achieved through a cognitive behavioural treatment approach as shown by this study and others.

5.7 Overall Conclusion

The aim of the present research was to develop a measure of perception of coping (for use with patients diagnosed of progressive/chronic physical illnesses) and to validate the developed measure with other standardised measures.

This has now been completed. Although the PCS showed good reliability it failed to show validity with the few scales used here.

It was also the intention of this study to demonstrate that negative perception of coping can be modified by way of rehabilitation interventions and Cognitive Behaviour Therapy approaches. Two case studies were presented to emphasise the role of Cognitive Behavioural Interventions in improving negative perception of coping in Multiple Sclerosis patients. Further evidence for Cognitive Therapy approaches was also shown with the Chronic Pain Patients.

Although the out come of this research is positive it is premature to generalise as the validation of the PCS is yet to be established. However, data collection with the Pain Group continues and the scale will be validated later with a larger sample size of at least 150 subjects. Data collection will also be attempted with Multiple Sclerosis patients using other measures of personality characteristics.

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Appendix 1

THE
GENERAL HEALTH
QUESTIONNAIRE
GHQ 28
David Goldberg

Please read this carefully.

We should like to know if you have had any medical complaints and how your health has been in general, *over the past few weeks.* **Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.**

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation

Have you recently

A1 - been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much than usual
A2 - been feeling in need of a good tonic?	Not at all	No more than usual	Rather more than usual	Much more than usual
A3 - been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
A4 - felt that you are ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
A5 - been getting any pains in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A6 - been getting a feeling of tightness or pressure in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A7 - been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual
B1 - lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
B2 - had difficulty in staying asleep once you are off?	Not at all	No more than usual	Rather more than usual	Much more than usual
B3 - felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
B4 - been getting edgy and bad-tempered?	Not at all	No more than usual	Rather more than usual	Much more than usual
B5 - been getting scared or panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual
B6 - found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
B7 - been feeling nervous and strung-up all the time	**Not at all**	**No more than usual**	**Rather more than usual**	**Much more than usual**

C1 - been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
C2 - been taking longer over the things you do?	Quicker than usual	Same as usual	Longer than usual	Much longer than usual
C3 - felt on the whole you were doing things well?	Better than usual	About the same	Less well than usual	Much less well
C4 - been satisfied with the way you've carried out your task?	More satisfied	About same as usual	Less satisfied	Much less satisfied
C5 - felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful	Much less useful
C6 - felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
C7 - been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual

D1 - been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
D2 - felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
D3 - felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual
D4 - thought of the possibility that you might make away with yourself?	Definitely not	I don't think so	Has crossed my mind	Definitely have
D5 - found at times you couldn't do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual
D6 - found yourself wishing you were dead and away from it all?	Not at all	No more than usual	Rather more than usual	Much more than usual
D7 - found that the idea of taking your own life kept coming into your mind?	Definitely not	I don't think so	Has crossed my mind have	Definitely

A □ B □ C □ D □ TOTAL □

Appendix 2

THE HOSPITAL ANXIETY AND DEPRESSION SCALE

Name: **Date**:

This questionnaire will help you to let us know how you are. Read each item and underline the response which comes closest to how you have felt in the last few days. Don't take too long over your replies, your immediate reaction will probably be more accurate than a long thought-out response.

I feel tense or "wound up"
Most of the time
A lot of the time
From time to time, occasionally
Not at all

I still enjoy the things I used to enjoy
Definitely as much
Not quite so much
Only a little
Hardly at all

I get a sort of frightened feeling as if something awful is about to happen
Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

I can laugh and see the funny side of things
As much as I always could
Not quite as much now
Definitely not as much now
Not at all

Worrying thoughts go through my mind
A great deal of the time
A lot of the time
From time to time but not too often
Only occasionally

I feel cheerful
Not at all
Not often
Sometimes
Most of the time

I can sit at ease and feel relaxed
Definitely
Usually
Not often
Not at all

I feel as if I am slowed down
Nearly all the time
Very often
Sometimes
Not at all

I get a sort of frightened feeling like "butterflies" in the stomach
Not at all
Occasionally
Quite often
Very often

I have lost interest in my appearance
Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

I feel restless as if I have to be on the move
Very much indeed
Quite a lot
Not very much
Not at all

I look forward with enjoyment to things
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

I get sudden feelings of panic
Very often indeed
Quite often
Not very often
Not at all

I can enjoy a good book or radio or TV programme
Often
Sometimes
Not often
Very seldom

Appendix 3

COPE SCALE

On your answer sheet find the box marked "form". in that box, if you are female, code "1", if you are male, code "2".

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel, when *you* experience stressful events. Obviously different events bring out somewhat different responses, but think about what you *usually* do when you are under a lot of stress.

Then respond to each of the following items by blackening one number on your answer sheet for each, using the response choices listed just below. Please try to respond to each item *separately in your mind from each other item.* Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer *every* item. There are no "right" or "wrong" answers, so choose the most accurate answer for YOU - not what you think "most people" would say or do. Indicate what YOU usually do when YOU experience a stressful event.

1	=	I usually don't do this at all
2	=	I usually do this a little bit
3	=	I usually do this a medium amount
4	=	I usually do this a lot

1. I try to grow as a person as a result of the experience.
2. I turn to work or other substitute activities to take my mind off things.
3. I get upset and let my emotions out.
4. I try to get advice from someone about what to do.
5. I concentrate my efforts on doing something about it.
6. I say to myself "this isn't real".
7. I put my trust in God.
8. I laugh about the situation.
9. I admit to myself that I can't deal with it, and quit trying.
10. I restrain myself from doing anything too quickly.

11. I discuss my feelings with someone.
12. I use alcohol or drugs or make myself feel better.

13. I get used to the idea that it happened.
14. I talk to someone to find out more about the situation.
15. I keep myself from getting distracted by other thoughts or activities.
16. I daydream about things other than this.
17. I get upset, and am really aware of it.
18. I seek God's help.
19. I make a plan of action.
20. I make jokes about it.

21. I accept that this has happened and that it can't be changed.
22. I hold off doing anything about it until the situation permits.
23. I try to get emotional support from friends or relatives.
24. I just give up trying to reach my goal.
25. I take additional action to try to get rid of the problem.
26. I try to lose myself for a while by drinking alcohol or taking drugs.
27. I refuse to believe that it has happened.
28. I let my feelings out.
29. I try to see it in a different light, to make it seem more positive.
30. I talk to someone who could do something concrete about the problem.

(Check to see that you have completed exactly 30 items on your IBM sheet; then turn this page over and continue with the items on the other side.)

Continue to answer each item with these response choices:

1	=	I usually don't do this at all
2	=	I usually do this a little bit
3	=	I usually do this a medium amount
4	=	I usually do this a lot

31. I sleep more than usual
32. I try to come up with a strategy about what to do.
33. I focus on dealing with this problem, and if necessary let other things slide a little.
34. I get sympathy and understanding from someone.
35. I drink alcohol or take drugs, in order to think about it less.
36. I kid around about it.
37. I give up the attempt to get what I want.
38. I look for something good in what is happening.
39. I think about how I might best handle the problem.
40. I pretend that it hasn't really happened.

41. I make sure not to make matters worse by acting too soon.
42. I try hard to prevent other things from interfering with my efforts at dealing with this.
43. I go to movies or watch TV, to think about it less.
44. I accept the reality of the fact that it happened.
45. I ask people who have had similar experiences what they did.
46. I feel a lot of emotional distress and I find myself expressing those feelings a lot.
47. I take direct action to get around the problem.
48. I try to find comfort in my religion.
49. I force myself to way for the right time to do something.
50. I make fun of the situation.

51. I reduce the amount of effort I'm putting into solving the problem.
52. I talk to someone about how I feel.
53. I use alcohol or drugs to help me get through it.
54. I learn to live with it.
55. I put aside other activities in order to concentrate on this.
56. I think hard about what steps to take.
57. I act as though it hasn't even happened.
58. I do what has to be done, one step at a time.
59. I learn something from the experience.
60. I pray more than usual.

APPENDIX 4

CHRONIC ILLNESS:

PERCEIVED CONTROL SCALE (PCS)

DATE: DIAGNOSIS:

NAME: DATE OF DIAGNOSIS:

ADDRESS: MARITAL STATUS:

SEX: DO YOU LIVE ALONE: Y/N

DOB:

This scale will help us to find out about how you are managing your problem at present.

Read each statement and underline the response which comes closest to how you have felt in the last week or so.

Don't take too long over your replies, your immediate reaction will probably be more accurate than a long, thought-out response.

Thank you very much for completing this scale.

1. Coming to terms with the diagnosis and the disease will make all the difference in coping with my illness.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
2. Being in control of my illness depends on my individual effort.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly

3. Positive thinking plays an important part in controlling my illness.	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
4. Keeping myself cheerful helps me to control my illness	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
5. Finding a "happy medium" or "striking a balance" allows for improvement in my coping with the illness	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
6. The course of illness can be altered by way of thinking positively	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly
7. Mental strategies such as "mind over matter" help alter the course of the illness.	Agree Strongly	Agree Strongly	Neutral	Disagree Slightly	Disagree Strongly
8. Drugs are the only agent that enables me to cope with my exacerbation of symptoms	Agree Strongly	Agree Slightly	Neutral	Disagree Slightly	Disagree Strongly

APPENDIX 5

NAME:_____

WEST HAVEN-YALE MULTIDIMENSIONAL PAIN INVENTORY (WHYMPI)

Please indicate how much you agree with the following statements on a scale of 1-7.

1= very strongly disagree
2= strongly disagree
3= disagree
4= neither agree nor disagree
5= agree
6= strongly agree
7= very strongly agree

Scale 1: Interference

Pain affects my ability to participate in social activities _
Pain affects the amount of satisfaction I get from social activities _
Pain affects my ability to work _
Pain interferes with my daily activities _
Pain affects my ability to do household chores _
Pain affects the amount of satisfaction I get from family activities _
Pain affects the amount of satisfaction I get from work _
Pain affects friendships outwith my family _

Scale 2: Support

My spouse worries about my pain problem _
My spouse is helpful in dealing with my pain problem _
My spouse pays a lot of attention to my pain problem _

Scale 3: Pain severity

My pain has been severe during the past week _
I have suffered a lot because of pain _
My pain is severe at the present moment _

Scale 4: Self control

I have been unable to control my life in the past week _
I have been unable to deal with my problems in the past week _

Scale 5: Negative mood

I have been irritable during the past week _
I have felt tension or anxiety during the past week _
My overall mood has been low during the past week _

WHYMPI PART II SIGNIFICANT OTHER PERSON RESPONSE SCALES

The next group of questions concern your husband or wife or significant other person in your life. If you live alone, please go on to part III. Please indicate how often the following events occur on a scale of 1-6.

1= never
2= rarely
3= occasionally
4= often
5= frequently
6= very frequently

Scale 1: Punishing responses

My spouse expresses irritation at me _
My spouse expresses frustration at me _
My spouse expresses anger at me _
My spouse ignores me _

Scale 2: Solicitous responses

My spouse gives me pain medication _
My spouse gets me something to eat _
My spouse takes over my chores _
My spouse asks how he/she can help _
My spouse turns on the TV _
My spouse gets me to rest _

Scale 3: Distracting responses

My spouse involves me in activities _
My spouse talks to me to take my mind off the pain _
My spouse encourages me to work on a hobby _
My spouse reads to me _

WHYMPI PART III ACTIVITIES SCALE

Scale 1: Household chores

I can prepare a meal _
I can help with house cleaning _
I can wash dishes _
I can do laundry _
I can go grocery shopping _

Scale 2: Outdoor work

I can work on house repairs _
I can wash the car _
I can mow the lawn _
I can work on the car _
I can work in the garden _

Scale 3: Activities away from home

I can take a trip _
I can go out to eat _
I can go to a movie _
I can take a ride in the car _

Scale 4; Social activities

I can visit relatives _
I can visit friends _
I can go to the park or beach _
I can play cards or other games _

APPENDIX 6

PAIN RELATED SELF-STATEMENTS SCALE (PRSS)

The following statements are typical thoughts of people in pain. We would like you to indicate how often such statements enter your mind when you experience pain using the following scoring system:

0= almost never
1= occasionally
2= sometimes
3= often
4= frequently
5= almost always

1)	I feel better when I relax	_
2)	I cannot stand pain	_
3)	I can do some things	_
4)	I cannot change my pain	_
5)	I must relax	_
6)	I can deal with it	_
7)	I need medication	_
8)	I will soon be better	_
9)	It will never stop	_
10)	I am a hopeless case	_
11)	Other things are worse than pain	_
12)	I can cope	_
13)	When will the pain be worse	_
14)	Pain gets to me	_
15)	I cannot go on	_
16)	Pain drives me crazy	_
17)	Distraction helps me	_
18)	I can help myself	_

APPENDIX 7

PAIN RELATED CONTROL SCALE (PRCS)

The following statements are typical attitudes and reactions to chronic pain. We would like you to indicate how much you agree with each statement using the following scale: 0= not at all

1= slightly
2= a little
3= in part
4= largely
5= very much

1)	I can predict pain	_
2)	I cannot influence pain	_
3)	Stress increases pain	_
4)	Only medicine or a doctor can help	_
5)	I am powerless	_
6)	I can do something about pain	_
7)	Pain is a matter of fate	_
8)	I cannot do anything	_
9)	I tried, but gave up	_
10)	I try to forget pain	_
11)	I am worried about the future	_
12)	I try to distract myself	_
13)	I do not give in, I fight	_
14)	Pain is a challenge	_
15)	I have learnt to live with it	_